PhD studentship: Developing and evaluating a parent-child intervention for children with Autism Spectrum Disorders: A feasibility study

Supervisory team: Dr Martin Cartwright, Prof. Dermot Bowler, Dr Sophie Lind.

1.) Full Title
Developing and evaluating a parent-child intervention for intellectually able children with Autism Spectrum Disorders: A feasibility study

2.) Background
Autism is a neurodevelopmental disorder typically manifest before the age of three years and characterized by difficulties with social interaction, communication, and restricted or repetitive behaviour (APA, 2013; WHO, 2016). The Centers for Disease Control and Prevention suggests that 1.7% of children in the US have ASDs (Baio et al, 2018). Extrapolating this to the UK population gives an estimate of 1.02 million individuals with ASDs, including more than 192,000 children (≤ 15 years). Adults with autism and primary caregivers of children with ASDs report significantly lower levels of health-related quality of life than the general population across a range of sub-domains (Roy & Dillo, 2018; Kuhlthau et al, 2014).

Intellectually able children with autism
Forty five percent (45%) of children with ASDs show no additional language or intellectual disabilities and are educated in mainstream schools. These children are frequently referred to as ‘high functioning’ (relative to intellectually-disabled children with ASD) but despite this their long-term outcomes are poor. They have poor educational attainments, are more likely to be unemployed, living on welfare and/or in subsidised housing, more likely to be in the lowest quintile of deprivation, and much less likely to have stable long-term relationships (Brugha et al., 2011). In addition to the huge personal cost to these individuals and their families, current financial support costs in the UK are estimated at ~£30 billion per annum (Buescher et al., 2013). There is now a large body of research showing that these children continue to experience difficulties in mental state understanding (‘theory of mind’) (Baron-Cohen, 1995), episodic memory (Bowler et al., 2007; Crane et al., 2009) and self-understanding (Lind, 2010). Recent research has shown an association between measures of episodic memory, psychological well-being and quality of life in older autistic adults (Roestorf, 2018). Yet most autism-related interventions target either very young children or older children with additional cognitive disabilities. Moreover, many such interventions are based on a ‘gap-filling’ model, attempting to teach missing skills rather than tackling underlying cognitive difficulties. The poor long-term outcomes and lack of theoretically-informed and empirically-supported interventions for school-age, non-intellectually-disabled children with ASD makes the development of acceptable and effective interventions an urgent priority.

The areas of psychological difficulty that continue to confront these children as they grow into adulthood have been reliably shown to improve in typical children when parents are taught to use a particular type of strategy when interacting with them. Despite the potential benefit of using this strategy with children with ASDs, to date no research has been conducted.

Aims: To evaluate the feasibility and acceptability of a novel parent-child interaction intervention for intellectually able children with ASD. To compare functional outcome
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measures for children receiving the novel intervention to those receiving an active control. Based on explicit *a priori* stop-amend-go criteria, to determine the readiness of the intervention for a future RCT.

### 3.) Methods

**Study 1 (review)**
A systematic review of effectiveness (and meta-regression, if appropriate) will evaluate relevant interventions conducted with typically developing and any available clinical child populations. The aim is to identify characteristics of intervention content or delivery associated with improved feasibility, acceptability or efficacy, to inform the pilot study. The review will be registered on PROSPERO and conducted and reported in line with PRISMA guidelines.

**Study 2 (pilot study)**

*Design*: A feasibility study, specifically a randomized pilot study (Eldridge et al, 2016), will compare the intervention based on (adapted) intervention protocols for typically-developing children to an active control condition (Joint Attention Training; JTA).

*Participants*: Parent-child dyads (comprising 5-10 year old children with ASD and WASI IQ >70) will be recruited from mainstream schools and specialist units/schools (25 dyads per trial arm).

*Outcomes*: Primary outcomes will be NIHR-recognised quantitative indicators of feasibility, and measures of acceptability, for the novel intervention condition. Secondary outcomes will include clinical and functional measures. Outcome measures will be administered at baseline and again at the end of the intervention period.

*Interventions*: JAT is a commonly applied procedure in autism research that will be used as an active control condition in the proposed research to ensure that parents and their children spend similar time interacting on a shared task but without the key ‘active ingredients’ of the novel intervention. Following established protocols for JAT, parents will be trained to take part in daily joint activities with their children. For each experimental condition parents will be asked to implement each intervention daily over an extended period. JAT has been used previously with children with ASD with at least one study suggesting potential benefits on some outcomes (Kaale et al, 2012); the novel intervention has never been used with children with ASD but it has a stronger theoretical basis for effectiveness (than JAT) and has shown evidence of benefits in typically-developing children. Given the current state of the available evidence, the novel intervention and JAT can be considered equipoised for the outcomes of interest.

The PhD candidate will proactively make weekly phone check-ins over the first 4 weeks, and then monthly check-ins for the remainder of the intervention period. The supervisory team and PPI group (see below) will support the candidate if problems are identified with either intervention. A record of these interactions with parents will contribute to the qualitative evaluation of the feasibility and acceptability of the interventions.
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Public Patient Involvement: A PPI group (N=6) comprising parents of children with ASD and individuals with ASD will be established to provide guidance on study materials (e.g. Participant Information Sheet and Consent Form), to advise on the delivery and content of the training and support for parents, to advise on unanticipated issues raised by participants in the study, and to input into the interpretation of study data. This group will meet at least four times across the course of the pilot study (see Gantt chart).

Ethical considerations: Although the research will not formally assess efficacy, all participants randomised to JAT will be offered the novel intervention at the end of the intervention period.

Study 3 (interview study)
On completion of follow-up outcome assessments, parents in the novel intervention condition will be invited to participate in a single qualitative interview to evaluate the (retrospective) acceptability of the intervention and study procedures (e.g. randomization process; baseline and follow-up assessment procedures). Interviews will be based on the Theoretical Framework of Acceptability (Sekhon et al, 2017) and the Necessity-Concerns Framework (e.g. Horne, 1997). The sample size will be determined in line with data saturation procedures for deductive thematic analyses (Francis et al, 2010).

Study 4 (online survey)
A brief online survey will recruit parents of children with ASD. The survey will briefly describe the novel intervention implemented in the pilot study and ask questions about their perceived need for the intervention, the acceptability of the intervention, and will elicit any concerns or suggestions to improve it. A large sample size will enable precise population estimates of quantitative variables and probable saturation for free text responses.

4.) Outcomes
The principal outcomes from the proposed PhD research will be new insights into:
- The efficacy of the novel intervention in typically-developing and potentially some (non-ASD) clinical child populations (Study 1)
- The feasibility of conducting a future RCT of the novel intervention for children with ASD (Study 2)
- Parents’ acceptability of participating in a trial and delivering the novel intervention over an extended period (Study 3)
- Parents’ perceived need for, and acceptability of, the novel intervention (Study 4)
- Practical improvements for the trial procedures, parental training and intervention content (studies 2, 3, 4)
- The overall readiness of the novel intervention for a future RCT for children with ASD.

5.) Importance for clinical impact
The potential clinical importance of the research is that if the novel intervention is assessed to be feasible, acceptable, and needed, it would be relatively cheap and straightforward to roll out at scale to improve the lives of a large population of people with ASD and their families. The work also has the potential to contribute significantly to theories about the cognitive underpinnings of autistic behavior.
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6.) Supervision Arrangements
The supervisory team will consist of Dr Martin Cartwright (School of Health Sciences), Professor Dermot Bowler (School of Arts and Social Sciences; SASS) and Dr Sophie Lind (SASS). Professor Emeritus Patricia Howlin (King’s College London) will be an External Collaborator. The interdisciplinary team combines knowledge and skills from cognitive, developmental, clinical and health psychology and behavioural science, and has a wide range of experience in a lab-based and applied health research. Supervision will typically occur through fortnightly meetings with academic supervisors, except during periods of heavy data collection activities.

7.) Candidate’s role
We are offering a PhD studentship with a structured plan of research. The candidate’s role, with the support of the supervisory team, will be to deliver all of the planned research to a high standard within the given timelines. Within the constraints of the protocol there will be scope for the candidate to shape aspects of the research. To deliver the core elements of the research the successful candidate will have a range of skills and experience including (but not limited to): systematic reviewing (including quantitative synthesis), conducting a feasibility study, analyzing quantitative data, conducting qualitative interviews, analyzing qualitative data (using deductive frameworks), setting up online surveys, delivering training for an intervention, communicating sensitively with parents of children with ASDs and with individuals with ASDs, leading PPI groups, and writing-up research to a publishable standard. Additional transferable skills are prerequisite.
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7.) Outline timetable (Gantt Chart)

| Research Activities          | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | 31 | 32 | 33 | 34 | 35 | 36 |
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| Study 1: Systematic Review  |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Study 2: Feasibility study  |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Study 3: Interview Study    |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Study 4: Online Survey      |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Final editing               |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
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8.) Selected references

**Clinical Area**


**Behavioural Theory**


**Methodology**