Adapting a specialized ADHD parenting programme for use with ‘hard to reach’ and ‘difficult to treat’ preschool children

Fiona McEwan1,2, Margaret Thompson1,2, Cathy Laver-Bradbury2,3, Harriet Jefferson1,2, Johanna Koerting1, Elizabeth Smith1, Mark Knowles1, Donna McCann1, David Daley4, Jo Barton5, Sue Latter6, Helen Elsey7 & Edmund Sonuga-Barke1,8

1Institute for Disorders of Impulse and Attention, Developmental Brain-Behaviour Laboratory, School of Psychology, University of Southampton, Building 44, Southampton, SO171BJ, UK. E-mail: mt1@soton.ac.uk
2CAMHS Solent NHS Trust, Southampton, UK
3Faculty of Health Sciences, University of Southampton, UK
4Division of Psychiatry and Applied Psychology, School of Medicine, University of Nottingham, UK
5North Staffordshire Healthcare Trust, CAMHS, Stoke on Trent, UK
6ODC Research Group, Faculty of Health Sciences, University of Southampton, UK
7Academic Unit of Public Health, University of Leeds, UK
8Department of Experimental Clinical & Health Psychology, Ghent University, Belgium

Background: Effective implementation of parent training programmes for preschool Attention-Deficit/Hyperactivity Disorder type is constrained by barriers limiting take-up and effective engagement by ‘hard to reach’ and ‘difficult to treat’ families. Method: We describe an evidence-driven adaptation and piloting of an existing empirically supported preschool ADHD parenting programme to address these problems. Results: The New Forest Parenting programme was changed substantially in terms of length; content and delivery on the basis of information gathered from the literature, from parents and practitioners, further modifications were made after the pilot study. Conclusions: The adapted-NFPP is currently being assessed for efficacy in a large multicentre randomized controlled trial.

Key Practitioner Message

- Parenting approaches can make a valuable contribution to the management of preschool ADHD
- However barriers exist to implementation related to the extra burden of developmental delay in children and the complicating role of mental health problems and serious life events in parents and families
- Parenting programmes need to be adapted and extended to improve outcomes in such families
- In the New Forest Parenting Programme we have added modules for children (e.g. sleep, sensory issues, speech and language difficulties and adults (e.g. parental ADHD and learning difficulties) and increased exposure and access to difficult to reach families.

Keywords: Parent training; new forest parenting programme; preschool children; Attention-Deficit/Hyperactivity Disorder; treatment barriers

Introduction

Attention-Deficit/Hyperactivity Disorder (ADHD) symptoms, common in preschoolers (Egger & Angold, 2006), affect daily functioning, are a risk for development and a burden to services (Pelham, Foster, & Robb, 2007). Parenting programmes for preschool ADHD are evidence based (Hutchings et al., 2007; Sonuga-Barke, Daley, Thompson, Laver-Bradbury, & Weeks, 2001). However, practical constraints (e.g. adverse family life circumstances) may undermine access and engagement and reduce effectiveness (Koerting et al., 2013). The New Forest Parenting Programme (NFPP), originally an eight week home-based package for ADHD preschoolers, combines insights from attachment, social learning and neuropsychological theories. It is delivered by experienced practitioners who tailor psycho-education and parenting strategies to promote authoritative/constructive parenting and enhance parent–child communication and relationship quality. It uses games and ‘teachable moments’ to develop children’s regulatory skills. In trials, it has reduced child ADHD and conduct problems and improved parent mental health and mother–child interaction quality (Thompson et al., 2009). Currently, there is no provision to address barriers experienced by ‘hard to reach’ and ‘difficult to treat’ families. We therefore
undertook an empirically driven process to adapt the NFPP for such families as part of a broader initiative (Programme for the Early Detection and Intervention in ADHD; PEDIA, 2009). First, we identified take-up and engagement barriers through a review of the literature (Koerting et al., 2013) and interviews with parents/practitioners (Smith et al., 2014). Second, expert clinicians, working with this evidence, adapted the NFPP. Third, the adapted-NFPP was piloted and further revisions were made. The current paper focuses on stages two and three as the systematic review and qualitative interviews to identify potential barriers have been previously published.

Producing a prototype adapted-NFPP

On the basis of the review of the literature and the interviews, a number of adaptations were made:

1. Programme length (13 sessions) to allow the programme to be delivered over a longer time interval for families who missed appointments.

2. An initial motivational session was included to enable engagement of parents.

3. Modules to address sleep, speech/language problems and developmental delay were added and tailored to the child’s needs.

4. Optional parental ADHD, depression and literacy modules were offered to address these parental issues when present.

New therapeutic techniques: mindfulness (short exercises for the parent to use themselves and with the child, to aid attention) and social stories (crafted scripts that parents can use with the child to help them with a situation they find difficult. For example, to stop a child who is hitting other children, the parent will prepare a story about the importance of ‘kind hands’ and why the parent would be pleased with her child for using his hands in a positive manner. Social stories are a particular useful medium for mothers who are not very literate or creative or where a child has autistic tendencies; Gray & White, 2001).

1. Motivational interviewing and communication skills were taught to therapists to help them better engage and ‘hold’ families.

2. Outreach to relevant professionals to encourage referrals was improved in response to parents’ responses in the interview (Smith et al., 2014).

Piloting the prototype

We aimed to: (i) check that adapted-NFPP could be delivered to different family types and; (ii) identify areas in need of further modification and improvement. Southampton and South West NHS and University of Southampton ethics committees approved the study. Twenty one families were referred from Sure Start centres/local health services. Two children were too young; three screened negative for ADHD and one had severe language delay. Three parents were too busy and three could not be contacted. The remaining nine families entered the pilot which began with an introductory visit by the therapists. Informed consent was taken from all families for the trial and the videoing/audiotaping of the sessions. Five sets of parents completed all 13 sessions; Drop outs occurred; during the initial visit; in week one (because of complications relating to a second child); week three (for personal mental health problems) and week six (following a period of therapist’s leave). Appointment rescheduling was extremely common and an additional 30% of appointments were offered. This led to the programme always being extended past the scheduled 14 week duration. All mothers were married/co-habiting and on state benefits. They ranged from ages 20 to 47 years. Children’s ages ranged from 3 to 5 years. Six mothers had mental health and/or literacy difficulties. Seven met cut-offs for mood disorder on the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) and four met cut-offs for ADHD on the CSC (Barkley & Murphy, 1998). Five had high scores on the Family Strain Index (Riley et al., 2006). Six children had learning difficulties and/or speech and language delays measured on PIP (Jeffree & McConkey, 1998). All children scored above threshold for combined type on the DISC ADHD module (Costello, Edelbrock, & Costello, 1985). All children displayed oppositional and defiant behaviours on the Eyberg Questionnaire (Eyberg, 1980).

Two therapists, with relevant experience (one a health visitor and one a psychologist with extensive child mental health experience), delivered the programme. There were 4 days of training and on-going face to face supervision using video- or audio-taped sessions. Five families were telephoned at 2, 4, 6 and two at week 10. All were interviewed at the end the programme. Parents were asked the following questions: Did the programme make sense? Parents understood the programme and appreciated the strategies: What aspects of the programme worked? Parents valued their time with therapists – especially it’s home based, non-judgemental, practical and tailored character. The session length was judged to be about right. All expressed interest in continuing the programme after its scheduled end. What aspects did not work? All parents would have liked a mixture of group and individual sessions. One family was confused about the difference between ‘quiet time’ where a child leaves a situation to calm down and ‘time out’ where a child is withdrawn as a sanction. Diaries were a problem for all mothers. One parent was concerned that the therapists would judge her use of punishment. Others were concerned their house might be deemed too untidy. Parents asked for additional guidance on sleep and feeding problems and how to deliver messages successfully for their children with poor language. Therapists’ feedback was consistent in many ways with the views of the parents. In addition, they highlighted issues around the ADHD label; the slow progress made due the need to take time to ‘hold families through change’ especially as many families had had negative childhood experiences of their own; parents’ difficulties with understanding, literacy and attention; the high rate of cancellations of appointments; the value of (i) ‘social stories’ to reduce their children’s aggressive behaviour; (ii) more sessions with children present to model strategies, and (iii) adapting handouts to a picture format.
Preparing the final version

Seven additional adaptations were made. The concept of pre-school ADHD was clarified for parents. Manuals/hand-outs were revised to make them more readable by parents and children with complex problems. Audio CDs and a simplified DVD were developed (Laver-Bradbury, Thompson, Weeks, & Sonuga-Barke, 2012). The number of appointment reminders/cards/calendars was increased. The use of behaviour diaries for families with learning problems was reduced. Emphasis on motivational training for therapists was increased.

Discussion

In addition to the specific modifications described, a number of general recommendations for interventions can be made. These include:

1. **High visibility and targeted ‘marketing’ through diverse and non-traditional venues:** Information about parenting programmes needs to be disseminated through non-traditional pathways and media including the internet and radio and television advertisements. This was because parents told us in the interviews that that not all families go to local services (Smith et al., 2014).

2. **Flexibility of delivery and timing:** Target families often had complex and sometimes chaotic lives. This can be compounded by a lack of personal organization skills and/or low mood. They are also likely to experience life events at short notice which require the rescheduling appointments. These factors, if not handled in a flexible way, will inevitably reduce the uptake and attendance in parenting programmes e.g. (Barlow, Kirkpatrick, Stewart-Brown, & Davis, 2005; Kazdin, Holland, & Crowley, 1997).

3. **Tailoring therapeutic components to family needs:** A careful and systematic assessment of parents’ needs and preferences at the start of therapy is crucial.

4. **Broadening range of resources for problems other than ADHD:** Like us other programmes have added non-ADHD modules. For instance, Chacko et al. (2009) added modules for single mothers; Sanders, Markie-Dadds, Tully, and Bor (2000) for parents with depression; and Day et al. (2011) suggested a ‘wrap-around service’ for families alongside local services.

5. **Highly trained, sensitive and motivated staff:** The ability to motivate parents and to ‘hold through change’ while dealing with issues in a sensitive non-judgemental manner is a pre-requisite for therapeutic success with this population. This is particularly true for parents who have had difficult childhoods. Therapist skill (Scott, Carby, & Alison Rendu, 2008) and a positive working alliance (Kazdin, Whiteley, & Marciano, 2006) are also important.

In summary, the adapted-NFPP addresses many barriers to effective engagement of ‘hard to reach’ and ‘difficult to treat’ families and created a potentially more effective intervention. The adapted-NFPP is being trialled in a large scale RCT (McCann et al., 2014).

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References


Trial: Study protocol for a randomised controlled trial comparing the efficacy of a specialist and a generic parenting programme for the treatment of preschool ADHD. Trials, 15, 142.


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