

ADAPTING A SPECIALISED ADHD PARENTING PROGRAMME FOR USE WITH “HARD TO REACH” AND “DIFFICULT TO TREAT” PRESCHOOL CHILDREN

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Abstract

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 pre-school ADHD parenting programme to address these problems.

Results: The New Forest Parenting Package 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.

Discussion: The adapted-NFPP is currently being assessed for efficacy in a large multi-centre randomised controlled trial.

Key words: Parent training; New Forest Parenting Programme; pre-school children; Attention-Deficit/Hyperactivity Disorder; treatment barriers.

Running head: The a-NFPP for “hard to reach” parents and children

Background

Attention Deficit/Hyperactivity Disorder (ADHD) symptoms, common in pre-schoolers (Egger & Arnold, 2006), affect daily functioning, are a risk for development and a burden to services (Pelham, et al, 2007). Parenting programmes for pre-school ADHD are evidence based (Hutchings, et al, 2007; Sonuga-Barke, Daley, Thompson et al., 2001). However, practical constraints (e.g., adverse family life circumstances) may undermine access and engagement and reduce effectiveness (Koerting, Smith, Knowles et al. 2013). The New Forest Parenting Programme (NFPP), originally an eight week home-based package for ADHD pre-schoolers, 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, Laver-Bradbury, Ayres 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, Koerting, Latter et al., submitted). 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.

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Producing a prototype adapted-NFPP: On the basis of the review of the literature and the interviews a number adaptations were made:

- Programme length (13 sessions) to allow the programme to be delivered over a longer time interval for families who missed appointments.
- An Initial motivational session was included to enable engagement of parents.
- , Modules to address sleep, speech/ language problems and developmental delay were added and tailored to the child's needs
- 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 and White, 2001)

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- Motivational interviewing and communication skills were taught to therapists to help them better engage and “hold” families.
- Outreach to relevant professionals to encourage referrals was improved in response to parents’ responses in the interview (Smith et al., in press).

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 three to five 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, Lyman. Spiel et al., 2006). Six children had learning difficulties and/ or speech and language delays measured on PIP (Jeffrey & 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 four 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 of 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 its 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 to 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 et al., 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., in press).
- 2) *Flexibility of delivery and timing:* Target families often had complex and sometimes chaotic lives. This can be compounded by a lack of personal organisation skills and/or low mood. They are also likely to experience life events at short notice

which require the rescheduling of. 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 et al., 2005; Kazdin, Holland, Crowley et al 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, Wymbs, Wymbs et al., (2009) added modules for single mothers; Sanders, Markie-Dadds, Tully et al., (2000) for parents with depression; and Day, Kowalenko, Ellis, 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, Rendu, 2008) and a positive working alliance (Kazdin, Whitley, 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, submitted).

Key Messages

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.

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References

- Barkley, R.A. & Murphy, K.R. (1998) Current Symptoms Checklist. Attention-deficit hyperactivity disorder: a clinical workbook (2nd ed.), *Guilford Press, New York* (1998).
- Barlow, J., Kirkpatrick, S., Stewart-Brown, S. & Davis, H. (2005) Hard-to-reach or out-of-reach? Reasons why women refuse to take part in early interventions *Children & Society* 19: 199–210.
- Chacko, A., Wymbs, B.T., Wymbs, F.A., Pelham, W.E., Swanger-Gagne, M.S., Gario, E., Pirvics, L., Herbst, L., Guzzo, J., Phillips, C., & O'Connor, B. (2009) Enhancing Traditional Behavioral Parent Training for Single Mothers of Children with ADHD. *Journal of Clinical Child & Adolescent Psychology*, 38(2), 206–218
- Costello E.J. Edelbrock C.S. Costello A.J. (1985) DISC-IV. Validity of the NIMH Diagnostic Interview Schedule for Children: A comparison between psychiatric and paediatric referrals. *Journal Abnormal Child Psychology* 13, 579–595
- Day, C., Kowalenko, S., Ellis, M., Dawe, S., Harnett, P., & Scott, S. (2011) The Helping Families Programme: a new parenting intervention for children with severe and persistent conduct problems *Child and Adolescent Mental Health* 16 (3) 167-171
- Egger, H. L., & Angold, A. (2006). Common emotional and behavioral disorders in preschool children: presentation, nosology, and epidemiology. *Journal of Child Psychology and Psychiatry*, 47(3/4), 313-337.
- Eyberg SM. (1980) Eyberg Child Behaviour Inventory. *Journal of Clinical Child Psychology*, 9,

Gray, C., White, W. L. (2001). *My Social Stories Book*. London. Jessica Kingsley

Hutchings, J., Bywater, T., Daley, D., Gardner F, Whitaker, C., Eames, C.

& .Edwards, R.T. (2007) Parenting intervention in Sure Start services for children at risk of developing conduct disorder: pragmatic randomised controlled trial. *British Medical Journal*. 334(7595) 678-682

Jeffree DM & McConkey R. (1998) Parent Involvement Project (PIP) Developmental Charts. Second edition. *Hodder Education Hodder Headline*

Laver-Bradbury, C., Thompson, M., Weeks, A. & Sonuga-Barke, E.J. (2002) Living with preschool ADHD. Directed by Phillips, P. and O’Riordan, T. *Solent NHS Trust*

Kazdin, A.E., Holland,L., & Crowley, M. (1997). Family experience of barriers to treatment and premature termination from child therapy. *Journal of Consulting and Clinical Psychology*, 65, 453–463.

Kazdin, A.E., Whitley, M., & Marciano, P.L. (2006) Child–therapist and parent–therapist alliance and therapeutic change in the treatment of children referred for oppositional, aggressive, and antisocial behaviour. *Journal of Child Psychology and Psychiatry* 47 (5) 436–445

Koerting, J., Smith, E., Knowles, M.M., Latter, S., Elsey, H., McCann, D.C., Thompson, M., & Sonuga-Barke, E. J. (2013) Barriers to, and facilitators of parenting programmes for childhood behaviour problems: a qualitative synthesis of studies of parents' and professionals' perceptions. *European Child and Adolescent Psychiatry* (in press)

McCann D, C., Thompson, M., Barton, J., Daley, D., Laver-Bradbury, C., Hutchings. J., Coghill,D., Maishman, T., Raftery, J.P. Chorooglou, M., Caddy, J. Dixon, E., Stanton,L. Taylor, E., Sonuga-Barke,E.J. submitted. Comparison of Preschool

Parenting Interventions (COPPI) 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

PEDIA (2009) (Programme for early detection and intervention for ADHD) Five year Programme Grant funded by National Institute for Health Research (NIHR) *RP-PG-0108-10061*

Pelham, W.E, Foster, E., & Robb, J.A. (2007) The Economic Impact of Attention-Deficit/Hyperactivity Disorder in Children and Adolescents. *Journal of Pediatric Psychology* 2007; 32(6) 711–727.

Riley, A.W., Lyman. L.M., Spiel. G., Döpfner, M., Lorenzo, M.J. & Ralston, S.J. (2006) The family strain index (FSI). Reliability, validity, and factor structure of a brief questionnaire for families of children with ADHD. *European Child and Adolescent Psychiatry*, 15 (Suppl 1), 72–78

Sanders, M.R, Markie-Dadds, C., Tully, L.A. & Bor, W. (2000) The triple P-positive parenting program: a comparison of enhanced, standard, and self-directed behavioral family intervention for parents of children with early onset conduct problems. *Journal of Consulting & Clinical Psychology* 68: 624–640.

Scott, S., Carby, A. & Alison Rendu, A. (2008) Impact of Therapists' Skill on Effectiveness of Parenting Groups for Child Antisocial

Scott, S., O'Connor, T.G., Futh, A., Matias, C., Price, J., & Doolan, M. (2010) Impact of a parenting program in a high-risk, multi-ethnic community: the PALS trial. *Journal of Child Psychology and Psychiatry*. 51(12) 1331-41

Scott, S., & Dadds, M.R. (2009) Practitioner Review: When parent training doesn't work: theory-driven clinical strategies. *Journal of Child Psychology and Psychiatry* 50, Issue 12 1441–1450

Smith, E., Koerting, J., Latter, S., Knowles, M.M., McCann, D.C., Thompson, M. & Sonuga-Barke, E.J Overcoming Barriers to Effective Early Parenting Interventions for ADHD: Parent and Practitioner Views. *submitted*

Sonuga-Barke, E.J., Daley, D., Thompson, M.J.J., Laver-Bradbury, C., & Weeks, (2001) Parent based therapies for attention deficit/ hyperactivity disorder: a randomised controlled trial with a community sample. *Journal of American Academy of Child and Adolescent Psychiatry* 40 (4) 402-408

Thompson, M.J.J., Laver-Bradbury, C., Ayres, M., Le Poidevin, E., Mead, S., Dodds, C., Psychogiou, L., Bitsakou, P., Daley, D., Weeks, A., Miller Brotman, L., Abikoff, H., Thompson, P., & Sonuga-Barke, E.J.S. (2009) A small-scale randomised controlled trial of the revised New Forest Programme for Preschoolers with Attention Deficit Hyperactivity Disorder *European Child & Adolescent Psychiatry* (10) 605-616

Zigmond, A. S., & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale, *Acta Psychiatrica Scandinavica* **67** (6): 361–370