

Strategies for engaging and keeping families in research studies: Key lessons from the Helping Children Achieve Trial

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This research report was commissioned before the new UK Government took office on 11 May 2010. As a result the content may not reflect current Government policy and may make reference to the Department for Children, Schools and Families (DCSF) which has now been replaced by the Department for Education (DFE).

The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Education.

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Executive Summary

Background

Recruiting families into an intervention study can be difficult. The Helping Children Achieve Trial aimed to recruit 240 families from the London Borough of Hackney and Plymouth. Families with a child aged 5-7 with antisocial behaviour were invited to take part in a trial to test which of four interventions were most effective in reducing the risk of antisocial behaviour and improving literacy.

Finding families who met the criteria for inclusion and then were willing to take part in the intervention was challenging. To meet the target of 240 families, over 3000 families were screened to see if they met the criteria for inclusion. This makes the trial one of the biggest ever surveys of primary school aged children's antisocial behaviour in inner city areas in the UK.

For the benefit of other researchers carrying out research into families with children, the Department of Education (DfE) as sponsors of the study asked the NAPR research team to document and share their experiences of recruiting families into trials and summarise the strategies that they found worked best.

This paper is based on a fuller account *Challenges recruiting families with antisocial children into intervention trials: lessons from the Helping Children Achieve Study* by Dr Milena Stateva, Jacqueline Minton, Dr Celia Beckett, Dr Moira Doolan, Dr Tamsin Ford, Dr Angeliki Kallitsoglou, Professor Stephen Scott and the HCA research and intervention teams submitted to *the Journal of Children's Services* and due for publication early in 2012.

Description of the HCA Study

Families with a child aged 5-7 with antisocial behaviour were recruited into an intervention trial in Hackney and Plymouth between 2008 and 2010. The aim was to compare the effectiveness of three evidence-based parenting group interventions and usual services to reduce the level of antisocial behaviour and improve the literacy of children in Year 1 and Year 2.

The 4 interventions were:

- The **Incredible Years** (IY) a well known programme for groups of parents which is designed to improve parenting, reduce child behavioural problems and improve child and parent relationships;
- **Supporting Parents with Kids' Education in School** (SPOKES), a relatively new British programme for groups of parents is designed to improve parents' ability to support child reading development and improve child literacy;
- Both programmes in combination IY-SPOKES (**COMBI**); or

- Service as usual/‘**Signposting**’ which provides information to parents about services that are appropriate for concerns they raise about their child. This was the control condition.

The HCA study was conducted in two contrasting local authorities. Hackney is an inner London borough with a diverse ethnic population and as one of the most socio-economically deprived borough in England. In contrast, in Plymouth 95% of the population is White British. Plymouth is 84th out of 152 local authorities for deprivation but the schools chosen were in the poorer parts of the city.

Design

The HCA trial is a four stage study.

Stage 1: children in Year 1 and Year 2 were screened for antisocial behaviour using a brief questionnaire. Children with scores on this questionnaire that suggested that they are at risk of significant antisocial behaviour are invited for further assessment by an interview with the parent.

Stage 2: families who met the eligibility criteria and agreed to the study were randomly assigned to one of the interventions or control group. Assessments were carried out at 6 and 12 weeks after the start of the intervention.

Stage 3: recruited families were fully assessed again, 9 to 11 months after the first full assessment

Recruitment Procedure

Screen

All children in Year 1 and 2 classes were screened in selected schools in Hackney and Plymouth. Parents were sent a letter in their child’s school book bag from the HCA research team informing them about the screen and enclosing a questionnaire. Trained researchers would then be in the playground for a number of days at the start of school or end of the day collecting the questionnaires from parents. Parents were compensated with a £5 voucher for the time they took to complete the questionnaire.

Teachers were also sent a letter by the HCA and invited to complete a questionnaire for each child in their class. To compensate teachers for the time this took, they were covered by a supply teacher. In addition, some families (n = 262) were referred to the study, either directly, or following discussions with teachers or parent support advisers.

Parents were also invited to take part in the study through adverts in the local press and GP centres, school parents' evenings and coffee mornings. They were asked to complete the screening questionnaire if they thought that their child was experiencing behavioural difficulties.

Participants were eligible to take part based on the following criteria:

1. Children met the screen cut-off
2. Parent and child's ability to speak functional English
3. Interest in taking part in the study
4. Child score equal or above 0.7 on the Parent Account of Child Symptoms, Disruptive Behaviour scale
5. Child free of global developmental delay
6. Child score equal or above 70 on the British Picture Vocabulary Scale, a test related to general cognitive ability.

Summary of factors affecting continuation in the trial

To encourage attendance, parenting groups were run in familiar environments, such as the schools the children attended or the local children's centre.

Every effort was made to try and encourage parents to participate by reducing barriers to participation. Including financial assistance with transport and/or child care. Despite these efforts it still proved difficult to get some parents to attend - particularly in Hackney.

Overall, 42% of families who consented to taking part in the study did not attend the intervention. Some dropped out of the research project before randomisation others at the start of the parent group. Common reasons were time commitments and lack of commitment to the programme. Furthermore, some families were later found to be ineligible. Families who did not speak English at home were less likely to engage in the study.

Families were more likely to drop out in Hackney (53%) than in Plymouth (35%). The reasons for families dropping out in Hackney were varied and complex. These ranged from concerns about personal safety when going out at night, to difficulties in understanding the trial because English was not the first language; to other time commitments particularly for working mothers, as well as lack of motivation to attend.

Although there is a high rate of drop out from the study this was not related to demographic factors other than the difficulties of English as a second language. It probably relates mostly to the constraints of being a research programme and a

lack of flexibility on the days on which interventions can be provided, etc.

The families who stayed committed to the interventions tended to be those whose children had the greatest level of conduct difficulty and who may therefore had the most to gain from the intervention.

Once participants became involved in the interventions there was a very high level of commitment with the over 70% attending at least half or more of the course

Some of the key lessons from recruiting families to the Helping Children Achieve Trial are summarised below.

1. Recruiting families into trials

Recruiting families into a study can be challenging. Common obstacles to getting involved include:

- **Time demands:** Taking part in a study demands a lot of time and commitment from parents. Attending the intervention itself takes up substantial time (often many sessions over many months). In addition, there are more demands on the family's time for assessments before, during and after the intervention.
- **Concerns about privacy:** Parents are asked to reveal personal information about themselves, their partners and their children. This can be off putting.
- **Stigmatising effect of participating:** Parents may feel they or their family might be "singled out" and stigmatised as having problems if they take part.
- **Disappointment:** If families agree to get involved and become part of a randomised controlled trial, they have to accept that they may be allocated to either the part of the trial that receives the active intervention or the part that doesn't.

All the above factors mean that the recruitment process requires considerable thought and care to engage families who are willing to participate in the intervention and also likely to stay with the study.

2. Key strategies for getting and keeping families in trials

a. The right research team

Hire researchers who have both warm personable characteristics and academic excellence

Intervention studies need to use researchers who are able to work well when in extensive and intimate contact with families and other relevant agencies. It's therefore very important to consider personal qualities in addition to academic knowledge and expertise, when appointing researchers who'll be working with families.

Human qualities are crucial. Researchers must have excellent 'person' skills - warmth, empathy, patience, and excellent communication skills as well as general problem solving abilities and flexibility. These are a must because the relationship is long term and working with some families can be tricky.

Researchers who reflect the community and the culture of the area that the research is being carried out in are a huge asset. They can help find the right way to communicate effectively with parents, build up their trust, encourage participation, etc. as well as inform the research in project planning and deciding which approaches might be best to use.

b. Work closely with schools

Studies investigating interventions for children with problems (such as antisocial behaviour or attention difficulties) that aim to improve matters for the whole population (rather than just the children of parents who put themselves forward) are very likely to involve schools. Schools offer good access to children and parents and being involved in an intervention through a school can be less stigmatising for parents who want to participate. Lessons from the HCA study suggest that the following considerations are important:

❖ **Identify the right schools to work with**

- **Choose a school that is interested in the study and has the time and capacity to get involved.** Schools under special measures or going through changes such as a new Head teacher, significant staff changes, building works, funding problems, etc are unlikely to be able to meet the demands of a large intervention study and shouldn't be used.
- **Involve the intervention team.** If the intervention team are part of an established service that the school knows or already uses, uptake is likely to be higher because they see them as an important resource and already trust them. Targeting these

schools is likely to be more fruitful than trying to recruit schools that have no previous engagement with similar services.

- **Take account of established services in schools.** Researchers need to make sure that the school is not already involved in interventions similar to or the same as those being offered in the study. This will affect parents and children's ability to take part in the study as well as distort findings.

❖ **Establish effective co-ordination between school and the research team**

The key principle in working with schools is that the study must acknowledge and work around the school's routines and practices – not the other way around.

- **Obtain agreement to participate in the study** in writing from the Head Teacher.
- **Give in depth information about the study** to the Head and other key staff. This includes written material as well as discussions and Q &As at face-to-face meetings with senior staff from the study. The more staff understand the study, the more likely they are to explain it to parents and to encourage involvement and add to its success.
- **Clearly identify the study team**, explain their roles and responsibilities and make it clear to the school staff who should be contacted for what. Best practice is to have one or two people from the study who are named as key contacts for the school. Ideally, a senior member of staff at the school (e.g. Special Educational Needs Co-ordinator) should be identified to work with the study's co-ordinator, to make sure that there is careful planning and a clear and concise information exchange. It's also helpful to have a named researcher who can organise key operational tasks with the school and who is known by the school's secretarial and admin team. Building trusting relationships is vital and these measures help enormously because they give clarity.
- **Plan around the school calendar** so that the school is not over burdened at busy times or when children and staff are off site, parents and staff are attending parents evenings and to ensure that school staff are around and available to provide assistance. This approach will help the study to meet key milestones.
- **Close co-ordination with the school** can also help in identifying opportunities to meet parents and potential participants in the study.
- **Provide information to parents and the school staff** through newsletters or email updates to help raise awareness, keep the study in mind, help with communication and ultimately, increase the likelihood of participation in the study.
- **Show appreciation to the school staff throughout the study.** Researchers need to make sure they are appreciative and grateful to staff whenever in schools and gestures such as boxes of fruit, biscuits or treats for the staff room help engender good relationships.

❖ Working collaboratively with parents

Initial Engagement

Parents are busy people. They are often balancing family responsibilities with work, training, education or other complex challenges such as caring for parents or dealing with other demanding family and life issues. Many people are not familiar with research studies and are anxious about participating.

- **Encourage active involvement from staff that parents trust:** for example, getting the Head Teacher, SENCO and key support staff involved gives another channel to explain to parents what the research is about and can encourage participation. This can be backed up with information provided formally in newsletters and flyers or informally in the playground and in face to face encounters with parents.
- **Availability and visibility:** it helps to have a team of researchers in the playground at drop off and pick up times, dressed in T-shirts and caps with the study logo or name badges and giving out handouts for parents explaining the study. The research staff need to be engaging and available to explain the study, answer queries and help parents with completing forms.
- **Accessible and engaging information:** information needs to be pitched at the right level and in a way that is accessible, e.g. straight forward language, pictures and figures so that it can be understood by all parents including those with poor literacy or working in a second language.
- **Offering small incentives helps increase participation:** vouchers (for example, shopping vouchers worth £5) or small boxes of chocolates, small goody bags, etc are popular with parents and encourage completion of initial “screen” questionnaires.
- **Informal contact:** written contact from the study needs to be backed up with more informal face to face contact. Coffee mornings/afternoons, ‘drop-ins’ and researchers attending parent evenings are helpful in attracting some parents. Having posters around the school reception explaining the study also helps raise awareness.

Getting parents’ consent and maintaining interest in the study

Taking part in an intervention study requires an enormous commitment of time and interest from parents. Concerns about selection and randomisation must be discussed sensitively and in a way that parents understand. Building a relationship is crucial to minimising disruption and creating trust. Displaying empathy, and normalising the behaviours and difficulties experienced by the parents, helps to build an informal, ‘friendly’ atmosphere from the outset.

Successful strategies include:

- **Face to face meetings:** A face-to-face explanation of the randomisation process and the interventions by the research team, including handing out information sheets with illustrations for less literate parents or parents working in a second language.
- **Streamline assessments.** Make sure that questionnaires are relevant, and as short as possible to minimise the assessment time and reduce the burden on parents. Offer parents interviews at times convenient to them including evenings and weekends.
- **Using parent ‘graduates’ champions:** Including parents who have already done the intervention in the recruitment drive can help increase participation. They can answer questions or even be involved in a promotional DVD as “graduates” to help to provide a parent perspective on the interventions and champion involvement.
- **Different days and different times:** Offering interventions at different times, including some evenings and weekends helps increase the chance that parents can find a convenient time to attend.
- **Staying in touch:** Contact must be maintained with parents. Messages and updates by phone, email, sending cards or sending newsletters about the study helps maintain their interest and participation.
- **Keeping the study in parents’ and the school’s eye:** Having brightly coloured T shirts printed , distributing mugs, trolley key rings, stress balls, erasers, pencils, etc with the logo of the project helps raise consciousness and awareness of the study

❖ **Offer incentives**

Mugs, T shirts, erasers don’t only act to promote the study but act as incentives. These products are very cheap to buy when purchased in bulk from marketing suppliers and are popular with parents, teachers and children.

Parents were also given £5 vouchers for attending sessions in London because parents were harder to engage there than in Plymouth.

❖ **Close co-ordination between the research and the intervention teams**

In an intervention study, close co-ordination between the research team who study the effect of the intervention and intervention team delivering the intervention is crucial.

- **The research team will need to take account of the engagement and delivery times needed by the intervention team** to assure the intervention is successful.

- **Regular meetings between designated co-ordinators on both teams** are a must at key transition points, such as at recruitment times and the beginning of group programmes. This ensures that information between the teams is exchanged in a timely fashion

Formal referral procedures, including completion of referral forms, can assist in the transfer of information between teams.

Self referral or screen?

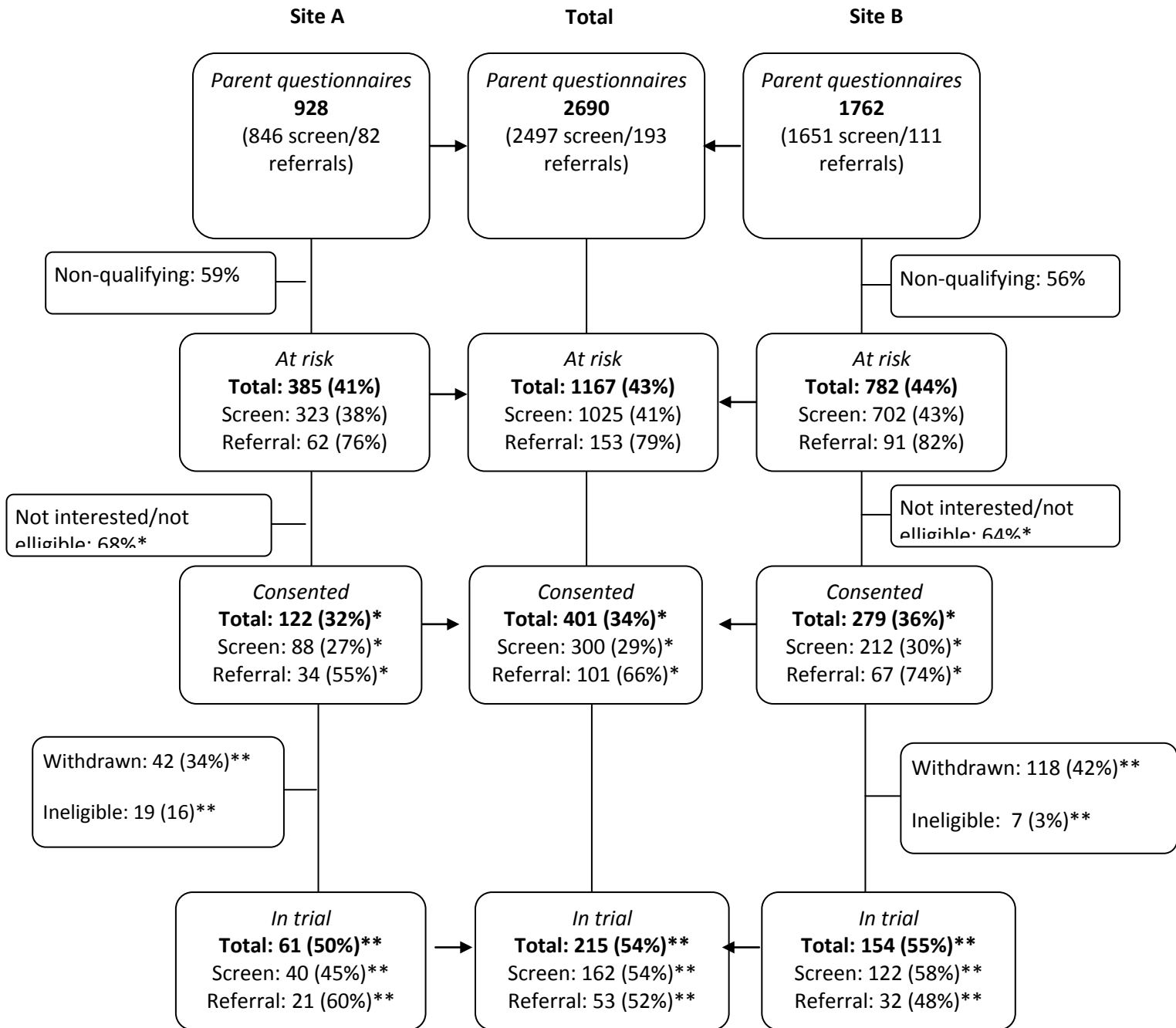
An interesting debate is which is more effective - self referral or screening?.

Screening reaches more parents but many families who aren't eligible are contacted hence the proportion eligible to take part is small. Referrals are more limited in number but a higher proportion are both eligible and likely to engage (i.e. the people with problems are more likely to come forward or be put forward by teachers, etc). The referral process is much harder and in this trial, the number recruited by screening was much higher. 162 families came through screening and 53 through referral.

Another important issue that affects the recruitment approach is if the study is an 'intention to treat'. For example, if the study aimed to test how many parents of children identified as being at risk of developing antisocial behaviour would accept a parenting program, a screening process would be necessary. If you wanted to test how many parents identified by professionals as having a problem would engage then that is a referral process.

Once engaged in the trial the drop out rate between the referred parents or screened parents are similar. The diagram below summaries the participant flow in the study.

Chart 1: Participant flow



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