Public Involvement in Research: Social and Emotional Well-being in Early Years

Final report following discussion groups held with parents and family service staff

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1. Introduction

The National Institute for Health Research (NIHR) has identified a need for research into interventions that can promote social and emotional well-being and improve the life chances of 0-2 year old children. In response to the resulting call (13/93), we propose conducting a study to establish the effectiveness and cost-effectiveness of the Incredible Years (IY) Infant and Toddler Parent Programmes in enhancing social and emotional well-being in children under two years of age, when delivered in doses proportionate to need. This report provides an overview of some preliminary 'public involvement' research undertaken to inform and enhance this work.

2. Summary of the proposed bid to be informed by this public involvement activity

Considerable research has shown that early childhood environments, and particularly parenting practices and parent mental health, can significantly impact a child's social and emotional competence, behaviour, and later life outcomes, such as educational attainment, the ability to form secure relationships, likelihood of criminality or alcohol/drug misuse, and mental health status (see Shonkoff, Garner, Siegal, Dobbins, Earls, McGuinn, & Wood, 2012; Kiernan, & Mensah, 2009; Melhuish, Sylva, Siraj-Blatchford, Taggart, & Phan, 2008).

Early intervention or prevention of mental health and behavioural issues is more effective, and less costly, than late interventions (Allen, 2011). In a recent high profile Cochrane review, group-based parent programmes for parents of children with conduct problems (aged 3-12 years) were shown to be effective, and cost-effective, in reducing parental depression and stress as well as negative/diminished parenting, whilst also enhancing positive parenting skills/practices, and children's social and emotional well-being and behaviour (Furlong, McGilloway, Bywater, Hutchings, Smith, & Donnelly, 2012). Nine of the thirteen identified studies involved Incredible Years (IY) programmes. A similar Cochrane review for parents of children aged 0-3 years (Barlow, Smailagic, Ferriter, Bennett, & Jones, 2010) stated that there is insufficient evidence to reach firm conclusions about the role of group-based parenting programmes in the primary prevention of social and emotional difficulties, and that more research is needed with this age group. The National Institute for Health and Clinical Excellence (NICE, 2012) has also highlighted the need for research to improve the evidence relating to interventions aimed at promoting social and emotional well-being in the early years.

The Basic IY programme (for parents of children aged 3 years and over) has a robust evidence base documenting positive effects on child well-being (and on parental mental health) in England, Wales, Ireland and elsewhere (see Mentinga, Oriobio de Castro, & Matthys, 2013). The more recently developed IY Infant and Toddler Parent Programmes, designed for parents of children aged 0-2 years, have not yet been rigorously evaluated in England. However, a non-targeted trial in Wales (Hutchings, Griffith, Bywater, Williams & Baker-Henningham, 2013) and a trial in health settings in the US (Perrin, Sheldrick, McMenamy, Henson, & Carter, in press) both show promising results for the IY Toddler programme, and a complementary trial including both the IY Infant and Toddler programmes in a non-proportionate universalism approach in Ireland (ie. on a fixed dose basis), has just begun.

We propose to undertake a randomised controlled trial (RCT) of the IY Infant (IY-I) and Toddler (IY-T) programmes for parents of children under two years of age. This would involve parents

being randomised to either intervention or control (services as usual) groups. Parents in the intervention group would further receive different 'doses' of IY, proportionate to their level of need; that is, those families at low risk of children developing social and emotional difficulties may receive an IY-I book, those at medium risk may receive the book *plus* the 10-week (2hrs/week) IY-I programme, and those identified at higher risk may receive the IY-I book, IY-I programme, *plus* a subsequent 12-week (2hrs/week) IY-T parent programme.

The primary child outcome would be child social and emotional well-being at two years of age. The primary main-carer outcome would be parent/carer well-being. Secondary outcomes would include; parenting skills and confidence, child behaviour, attachment, childhood injuries/service use frequency, nursery-school readiness, and cost-effectiveness.

This research would involve an 18-month internal pilot RCT leading to a definitive 30-month RCT. It is crucial to involve parents in the design of the research to explore ways of involving all significant carers in parent programmes and in research, such as fathers, step-parents and grandparents, including those who might be considered 'hard to reach'. We believe that such engagement and input would considerably strengthen the proposed research and the applicability and generalisability of the findings.

3. Background to parent involvement in research and service design

There is only very limited literature on the involvement of parents in the design of services and evaluation research on parenting. However, recent reports on parental engagement, and social inclusivity, (Axford, Lehtonen, Kaoukji, Tobin & Berry, 2012; Davis, McDonald, and Axford, 2012) suggest that parent involvement may be critical to overcoming common barriers in identifying, engaging with, and recruiting parents (including fathers and other primary carers) onto parenting programmes and subsequently retaining them in research.

A failure to identify, engage, recruit and retain parents can impact negatively on the quality and overall utility of the research in relation to:
- The number of participants per parent group; groups need a minimum number of participants to work well and be cost effective (i.e. groups need to be viable).
- As a result of the above, researchers may have to respond to a lack of participant numbers by being less strict in their eligibility criteria, but this may weaken any potential positive effects delivered by the programme.
- An over-representation of mothers in parenting research results in a lack of evidence about programme outcomes for fathers and other primary carers.

Possible solutions include:
- Working with practitioners and children's agencies to build relationships with potential service-users (parents) at the point of identification, engagement or referral. It is important to identify the most appropriate people/organisations in each context to forge these relationships with parents, which should be maintained throughout the process from identification to programme completion.
- Training service providers to identify and discuss perceived barriers to attendance for parents/carers, particularly those carers who do not typically engage with parent programmes (e.g. fathers and grandparents) and how to address them.

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- Managing parent/carer expectations of what a parent group is and what level of commitment is needed from them.

Sometimes it is difficult for services to engage with, and retain parents in parent programmes (see Whittaker and Cowley 2012); it may be even more difficult to recruit and retain parents to a parent programme that is being researched in an RCT due to the added complication of research visits to parents, requests for completion of measures at specific time points, and the possibility that parents may not receive a parent programme in the near future if they were randomised to the control condition.

Existing advisory groups such as NIHR's *INVOLVE* supports greater public involvement in NHS, public health and social care research, yet there is extremely limited evidence of parent/public inclusion in service design or in research on parent programme delivery and effectiveness.

4. Aims

Given the lack of information on public/parent involvement in this specific area (and with this particular age group of children), we applied for, and received, funding from the Research Design Service Yorkshire and the Humber region (RDSYH) in order to undertake a study designed to elicit parents' views and insights on:
- Identifying, engaging, recruiting, and retaining parents (particularly fathers and grandparents) within parent programmes.
- Identifying possible referral routes.
- Some aspects of study design (including randomisation, data collection processes, procedures and dissemination).
- Mechanisms for ongoing parent/public input throughout the development of the proposal and the lifetime of the project, including dissemination.

5. Method

The study involved a small number of focus group discussions and interviews with parents/carers who had previously attended, or were currently attending, a parent programme including, where possible, fathers and grandparents. We subsequently increased our target group to include parents who had not attended a parenting programme to include their views. Ethical approval was granted by the Department of Education Research Ethics Committee, University of York (20/11/13).

5.1.   The groups

Three discussion groups were held in the North-East and Yorkshire regions. The first discussion group (dgA) included mothers, fathers and grandparents (n=2), and the second (dgB) a father's-only group (n=2) as fathers are currently under-represented on parent programmes. The third group (dgC) consisted of mothers who had never attended a parenting programme (n=3). Each discussion group was one hour in duration and took place in a non-stigmatising and convenient location, such as community or family centres, thereby ensuring that the space provided was comfortable and familiar. Parents for the first two discussion groups (dgA and dgB) were invited to attend by their local service staff, such as their parent programme facilitator, whom they knew

and trusted. The parents for the third discussion group (dgC) were recruited through a local mother and baby group network.

Parent group facilitators attended the first two groups alongside the parents, and assisted the discussions by clarifying terms and experiences expressed by both parents and researchers. Facilitator attendance was agreed by both parents and researchers immediately prior to the commencement of the groups. In addition, service staff provided valuable additional information relating to their own area of work and experiences which related to the proposed research. An additional discussion group was conducted with a group of health visitors based in the North-West relating to our research proposal, outside of the RDSYH funding. Given that this related to our research proposal this has also been used to inform our findings. The views of service staff are reported in Section 5.6 below.

5.2.   The participants

In total, the sample for this study included nine parents. We originally anticipated that eight to ten parents would attend each discussion group. However, only two parents attended groups A and B. A further discussion group (dgC) enabled us to extend our discussion to those parents who had not attended a parenting programme, whilst a telephone interview (tiA) and a face-to-face discussion (ffA) were also conducted with two additional parents who were unable to attend a discussion group.

Of the nine parents involved in the study, six were mothers and three were fathers (a group we were particularly keen to learn from). One grandfather was invited to a discussion group but was unable to attend due to illness. The low attendance levels reflect the difficulties in recruiting parents to take part in research which the discussion groups were designed to explore and mitigate. Eight of the parents cared for more than one child, and four had been referred to a parenting programme by social services. Some parents had low literacy levels which provided researchers with useful information in terms of research participation. Five parents had recently attended a parenting programme.

5.3.   Addressing barriers to attendance

Each attendee received a £10 voucher as a 'thank you' for their time and contributions. Travel costs were offered but not claimed. One centre provided childcare to facilitate attendance, which was utilised by the parents. Refreshments were served at each venue.

5.4.   The procedure

The discussion groups were facilitated by the three lead authors, who are experienced in parenting programme research, and qualitative research methodologies.

Before the start of each group, the researchers explained the purpose of the discussion group and how the data would be used; they then obtained written informed consent for participation and for audio-recording the discussions. Parents were given an information sheet and had the opportunity to ask questions prior to the start of the group.

The researchers began the discussions by describing the research proposal, and ways of identifying parents to participate in the research, e.g. by health visitors, children's centre staff,

self-referral, etc. The researchers also explained why it is necessary to randomise in this instance. The three levels of intensity of the IY intervention were outlined (IY-I book only, book plus IY-I, book, plus IY-I and IY-T), and how families would be identified at each level. Data collection points and possible measures were also described briefly.

At the end of the discussion groups (and the face-to-face interview), parents completed: a) a receipt form to include their name and address for their 'thank you' voucher (and expense claim, if appropriate), and b) a feedback form, which included a web-link to the feedback form, for the RDSYH[1]. In addition parents were provided with a freepost postcard to provide the researchers with any additional comments or thoughts.

The telephone interview was structured in the same manner except for the fact that the information sheet was read out to the parent and the voucher, receipt and feedback forms were posted to the parent after the telephone interview and returned in a freepost envelope.

5.5.   The design

A hierarchical-type approach was applied to the design of the discussion group and interview schedules (Tomlinson, 1989). This enabled the researchers to prioritise the main research questions with each of the discussion groups (and with the one-to-one telephone and interview sessions). Follow-up prompts were only used if these (researcher-led) issues were not addressed in the subsequent discussion. Such a design enables parents to express their own priorities, which more direct or closed questioning does not, and is an efficient use of limited time (so as not to over-burden participants). It allows potential participants to be heard more fully, and for the parental 'voice' to take precedence. The 'open' questions encompassed in this design also often result in a more flowing discussion than 'closed', specific questions. This hierarchical design enabled researchers to address their main questions while acknowledging participants' concerns/priorities about research design, assessments, and communicating research findings. The addition of prompts encourages free-flowing dialogue and ensures that primary and secondary research questions can be addressed. By following this approach, we ensured comparability between groups whilst allowing participants to prioritise their own issues and concerns rather than them being solely determined by the researchers.

Our four priority research areas for discussion included:
1. Identification, engagement and recruitment to the study, and also to the parent programmes.
2. Retention of participants to parenting programmes.
3. Retention to study and data collection.
4. Next steps and continued public involvement throughout the study, including dissemination.

Within each of these areas, we identified one or two main, open-ended, questions, and several prompts if areas had not been sufficiently covered in discussions following the open-ended questions. The full list of questions and prompts is provided in the Appendix. In addition to the main questions and prompts the researchers asked for explanations/clarifications and encouraged group participation by asking inclusive questions such as 'Do you agree with that?',

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[1] Whilst all forms would be treated confidentially there was also a link which would enable participants to complete the survey on-line rather than returning a paper copy to the researchers. In the event all participants provided a paper copy to the research team.

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'How would that work in practice for you?', 'Have you got anything else you'd like to add?'. This technique ensured that all views were sought whilst facilitating clarification where necessary.

The main discussion points were summarised and fed back to the parents at the end of each group (or telephone/interview).

5.6.   Analysis

The digital recordings of the discussions were downloaded and shared amongst the research team together with the transcripts. It was decided to organise the data according to our main research questions, but also to analyse them for any additional emergent issues. Consequently, both thematic and grounded analyses were conducted (Hayes, 2000; Glaser & Strauss, 1967). A social constructivist approach was taken to the analysis (i.e.. individuals interpret new information through their existing knowledge, experience and beliefs) (Fosnot, 1996) as this was considered most appropriate to meeting the research aims.

5.7.   Service staff views

To supplement the discussion groups, we asked the family and children service staff (n=4) about their experiences and views on encouraging parents to take part in parenting groups and on retention. These additional discussions took place over the phone and face-to-face in a less structured manner, and in the absence of parents. They were an important complementary element to the discussion groups funded by the RDSYH. In addition, a discussion group was held with health visitors (n=6) by two other members of the research team and their findings have been incorporated into the suggestions for initial parent engagement (section 6.5.1).

6. Findings

Parents' views, as expressed in the discussion groups, are presented in sections 6.1-6.4 below. Section 6.5 provides the views of children and service staff on the key areas of interest. The four main areas of interest have been identified in Section 5.5 above. The findings for each are detailed below.

6.1.   Identification, engagement and recruitment to the study, and parent programmes

When researchers presented the RCT design (using visual aids such as those shown in Figures 1 and 2 below), the participants understood clearly why a control condition was necessary to establish if a programme was effective. Parents in dgA felt randomisation was a fair way of allocating parents to condition (control or intervention), although they wondered if control parents could have access to a 'parent support line'. When asked whether assignment to the control group would influence continuing participation in the project, one parent (tiA) said *"I would take part personally, yes, I would carry on because you need that control group to notice any difference really"*. The other two groups – dgB and dgC – did not discuss the randomisation aspect in any depth. However, all parents agreed that what it means to participate in a parenting programme, while also participating in a research study, needed careful explanation and clarification by researchers.

Some participants also suggested that promotional materials and the initial contact would result in successful recruitment if these highlighted the "selling points" of participation in the project for parents, whether that was in relation to the potential benefits for themselves or their children or for future generations.

Parents felt that they would be more likely to participate in a parent programme if they were approached by a parent similar to themselves in terms of socio-economic status and age-group, as well as being from the local area and having already attended a parent programme: *"Someone in the same position"*. This was particularly stressed by fathers who felt that similar fathers would *"speak the same language"* as themselves.

When asked whether a DVD of parents who had taken part in a parenting programme would be a useful motivating tool, the parents universally said they would prefer a more direct approach by a 'real' person so they could ask questions and discuss their own circumstances. All participants stressed the need for clear communication. One parent explained that *"knowing what is entailed from the outset is the crucial thing, knowing that you might not be selected if someone is really wanting to be selected and didn't get it – knowing that was a possibility is important. It's clear communication right from the beginning"*.

All participants agreed that the earlier in their child's life they were approached to participate in a parenting programme, the better. The parents were asked whether health visitors would be acceptable as a first contact point to discuss parent programmes. The parents in dgA and dgB thought a midwife may be more acceptable, and preferable in some cases as health visitors were perceived as being linked to social services – the parents involved in these two discussion groups reported negative experiences with the social services in the past. Midwives were generally viewed as being more 'neutral'. Parents in dgC felt that health visitors would be acceptable as long as they were fully informed on all aspects of the research, and potentially even accompanied by a researcher: *"you'd want them [the health visitor] to know as much as possible about the research project as possible… you'd want them to be fully briefed as there is nothing more irritating than someone not really knowing what they are talking about"*.

All parents felt they would be more open to advice early in their child's life as a preventative measure, rather than later, when they may be considered to be struggling with parenthood and in receipt of 'treatment' or intervention: *"Definitely before* [the baby was born]*, because once you've got a baby and you are nervous and when someone comes to see you, like, 'do you need a hand?', me personally, I took it as like, you're not coping, you need help and you feel like I'm not accepting that… I didn't want to go on one* [a parenting programme]. *I didn't feel I needed it"*. Self-referral was discussed briefly as a positive step by parents, although the facilitators had their reservations about this method (see Section 6.5 below). At least one respondent stated that they felt parenting programmes should be mandatory, and should start before the birth of a first child.

The location of the programme was viewed as important at it could be a barrier to attendance for those without cars, or for those with other children who needed to be taken to school or nursery or brought to the community/children's centre (buggies and prams on buses was anticipated as being a particular problem): *"I have a car but if you had to take two buses… if you could have one in your local community centre* [that would be helpful]… *If you've got no transport and you've got a buggy and your bairns, you are on that bus, finding that bus to get from here to there… you've got your nappies and your feed times, everything, it's a big trip"*.

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Figure 1: Enhancing Social-Emotional health and well-being in the Early years: A community-based RCT (and economic) evaluation of the Incredible Years infant and toddler (0-2) parenting programmes (E-SEE trial)
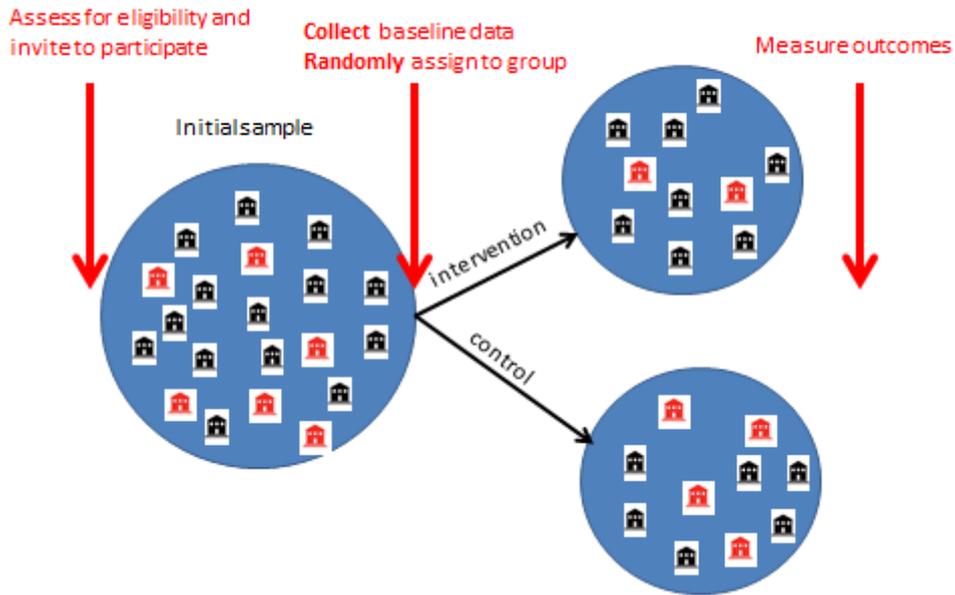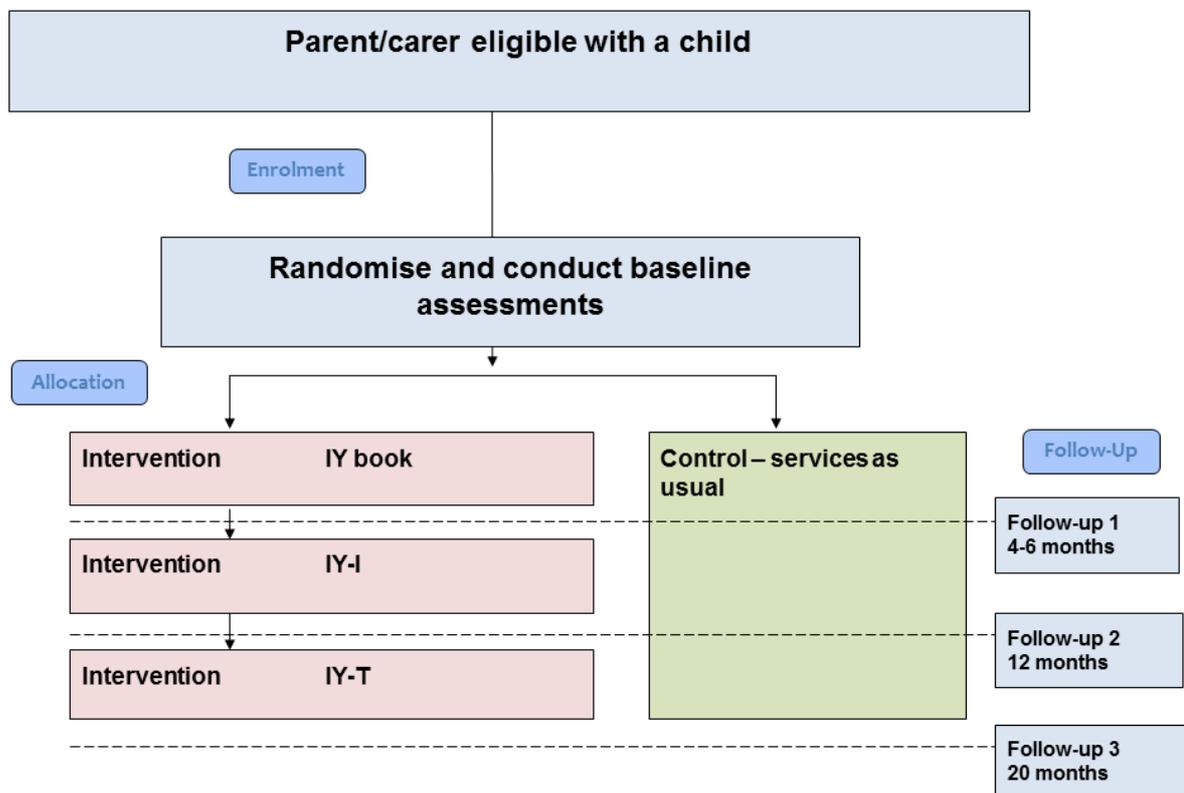

Figure 2: Randomised controlled trial design overview

6.2.   Retention of participants to parenting programmes

The researchers asked about retention to parenting programmes (to inform intervention arm allocation and service design). Having previously stated that 'nothing' would have enticed them to participate in a parent programme prior to being referred by social services, the participants were all very enthusiastic about the programmes they had attended.

One father had started attending a parent programme with his (now ex-) partner and continued, even after she stopped attending, due to the quality of programme, the delivery, the building of support networks, and his overall enjoyment of the course. He stated that he realised the support and knowledge gained were a valuable contribution to his family life. This suggests that methods of engagement, recruitment, and managing expectations is more an issue than actual adversity to attending a parent programme. In his words *''I didn't say a word at first''*; another discussant stated they felt initially *"shy"*.

The perceived barriers to attendance, included:
- Feeling being judged;
- Fear of the unknown – not knowing the facilitator or other parents;
- Transport;
- Child care;
- Time constraints; and
- Timing of course delivery.

Both of the above parents continued attending their parent programme despite the presence of such barriers. A common theme, or word even, used by the discussants in each group was *"normal"*, that attendance should feel 'normal' or that the other parents should be 'like them', people they could relate to, suggesting that both practical and social elements need to be in place for successful recruitment and retention.

The different levels of intervention were also clearly explained as there were concerns about potential participants' reactions to allocation to different levels of the intervention i.e. the idea of attending a ten-week IY-I course or attending the ten-week IY-I programme followed by a further 12-week IY-T course (ie. IY-I or IY-I + IY-T). Concerns over employment and attendance were raised, for example a working parent may find it difficult to commit to a 10- or 22-week course, especially if delivered during the day: "*if they only get one or two days off a week they may say yes but after a while they may think I don't have time*". An unemployed parent may also find employment during course delivery, which would affect attendance. In general, however, the length of programme was not seen as a barrier; in fact one parent was about to complete his first parent programme and had chosen to enrol on another after finding support and empowerment through attendance.

6.3.   Retention to study and data collection

It should be noted that none of the parents had taken part in research before, but many had participated in a parenting programme. All parents who had attended parent programmes agreed that at the point of referral to their current/recent programme they had felt unsure and did not know what to expect, and the context of a research project would understandably add to that uncertainty. However, the discussion surrounding retention to the *study* was quite limited as the

parents had had no experience of participating in research previously; therefore responses more often related to retention to a *programme* (see above).

The researchers clearly outlined the differences between being allocated to control and intervention groups. Incentives to programme (and research) participation were welcomed positively by over half of the parents, especially in relation to addressing barriers to attendance such as provision of transport, a non-stigmatising venue with crèche, plus a small payment for measure completion. Two parents felt that the research was worthwhile in itself, with participation giving a sense of empowerment and importance. One parent in dgC said *"I am quite happy to be involved in development, helping future generations for the better"*.

With regards to the use of incentives for measure completion, parents felt that such incentives were likely to be more important for retaining control group participants who had not received the intervention than for those who attended parenting programmes or received the IY book. Therefore, an additional incentive or motivator was felt to be important to retain them throughout the research such as being able to access the programme after completion of the research, or by being given access to a parent support telephone line throughout the research period.

In terms of data collection, it was explained that some data may be sensitive, in particular any information relating to parental depression and child health records. After some clarification, the idea of collecting this type of data was seen as acceptable provided that clear assurances of anonymity were made.

The length of time and regularity of data collection visits did not seem an issue as this was explained as being about an hour per round of data collection (at four data collection points over two years).

The ideal location for data collection was discussed and was felt to be subject to individual preference, but included home or community/children's centres. Consideration of this question was highly dependent on issues discussed above regarding parent programme attendance(e.g. ease of visiting a centre compared with remaining at home, especially with a young baby, feelings of being judged at home compared with meeting in a neutral space). However, this also raised sensitive issues regarding individual parental circumstances. As one parent who had attended a parenting programme stated: *"Now I'd say not a problem at home, but the thoughts in my head* [before] *would be that they were coming to pick my life apart, tear my house apart. I would think you are coming to spy on us"*. In contrast, another parent preferred the idea of a home visit because it would fit around her family life more easily: *"health visitors and midwives come*[ing] *to visit your house is quite good, even if researchers came to visit us rather than us having to go anywhere with the children… because then you don't need to worry… or disturb their* [the children's] *routine"*.

6.4.   Next steps and public involvement in research

The parents involved in the discussion groups all felt that they had a voice that would be worth listening to in terms of parent programme experience and methods of engagement and retention to inform the research proposal. For dgA and dgB participants, this was due to the high value they placed on their own programme attendance. Participants from both of these groups felt that parenting programmes were valuable at every stage of parenting, but earlier attendance (e.g. immediately after or just before birth), was preferable to 'later' attendance when problems had begun to emerge (as had occurred in the majority of their cases).

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The level of parent input and involvement in the proposed research varied but suggestions included the establishment of a parent advisory committee to:

- Assist with identification, engagement, and recruitment by being prepared to discuss their own experiences in attending a parent programme, either one-to-one or in a group format (the parents in dgA and dgB were prepared to assist in these roles, but did not feel confident enough to go 'on camera' to develop a DVD as promotional material);
- Review and input to promotional literature for the research study to ensure that it would be easily understood, which was particularly important for those with low literacy levels;
- Assess questions and measures researchers would like to ask participants; and
- Disseminate findings to other parents to hopefully encourage future participation in parent programmes or research.

6.5.   Parent programme facilitators' and family service staff experiences

As indicated in Section 5 above, parent programme facilitators, and family and service staff, engaged in discussions with the researchers focusing on the key areas explored in the parent discussion groups. One facilitator specialised in the recruitment and delivery of parent programmes to fathers, including very young fathers, both pre- and post-natally, as well as fathers of older age children.

Few staff had been involved in research studies in the past; hence, recruiting to a research study was not discussed in depth, and experiences and views on initial engagement focused on parenting programmes, retention, and public engagement to inform the research. The information gathered, however, could be utilised to engage parents in research trials.

6.5.1   Initial parent engagement

This section specifically related to engaging fathers, but similar approaches could be taken to engage with all parents/carers.

It was recommended that 'hook' events be conducted to encourage recruitment of fathers and that researchers should avoid using the word 'parent' or 'parenting' as fathers would generally interpret this as meaning 'mother' or 'mothering'. 'Hook' events could enable key workers to build trust with potential study participants prior to recruitment but may take 1-2 months to implement successfully.

Suggested events included (in order of delivery):

1. A fun event in the local area for fathers/carers to identify local parents (it is important at this event not to include any health messages)[2];
2. Work with schools to encourage children to make a personal invitation to fathers/carers to attend an additional fun event with their child to be held at the school/a local community centre. This event can promote father-child relationship building and should include a keep-sake memory of the day for both parties, e.g. a photograph.

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[2] These fun events do not have to be expensive – ie. for fathers a risk-taking/competitive or 'problem-solving' activity can be engaging, e.g. build a den, sports activities etc. A photo-shoot can also encourage participation as it builds shared memories between father and child/ren.

3. A further local fun event to continue building trust with family service staff. This event could include low-level recruitment consultations, e.g. 'what is it like to be a dad in this area?', 'what things are there to do with your child/ren around here?'
4. Invite fathers to discuss further what support they would like as a Dad in the area - to be held in a non-feminised family or community centre (issues were raised about children's centres being targeted at women through colours used, the display of domestic violence posters, etc). According to the insights we received, fathers at these invited discussion groups have typically requested support in being a dad – this can then open the door to an invitation to attend a parent programme with good buy-in and high retention levels.

Other suggested engagement and recruitment strategies included:

- Use of Children's Centres who may (depending on local practice) make a home visit in the first two weeks of a child's life. One of the organisations who facilitated a focus groups employs a young dads' worker who attends hospital scan clinics in the local area to talk to fathers at this stage of their partner's pregnancy.
- Using positive quotations from fathers' who have attended parenting programmes on promotional literature (but as indicated above, parents would prefer a personal recommendation – word of mouth being the best advertisement).

6.5.2 Retention of participants to parenting programmes

The current strategies employed by participating organisations were recommended:
- Establishing the importance of the course to each participant and assessing motivational factors. For example, for parents referred to a parent programme by the courts, a report written by the programme facilitator on the parent's progress could be a powerful incentive to attendance as it may, for instance, facilitate the early return of children to the home from a care environment;
- Organising an appropriate venue, small groups, and fun, short activities of 10-15 minutes each[3].
- Have a variety of delivery modes for any parenting programme, and ensure the facilitator is skilled and adaptable so the programme can be tailored to the group.
- Follow-up of any non-attendance immediately. This can include phone calls or a home visit. It was perceived as preferable to continue the programme on a one-to-one basis at home than have complete withdrawal from a programme.
- Timing of programme delivery is important and needs to take into account local circumstances and participants needs: 10am-12noon seems to be an ideal time for most, but certainly programmes should be delivered within the school day for parents with school-age children. Parents' possible shift work patterns may also need to be taken into account, which can make some 6-8pm groups attractive (although in dark winter evenings these may be less well attended). Saturday groups 11am-1pm were also reported as having been effective in some cases. In the areas where the discussion groups were held, it was estimated by service staff that approximately 60% of fathers attending parent programmes were unemployed, with less than 10% in full-time employment, and 30% undertaking temporary or shift work.
- Vouchers and group incentives were felt to be less important once a group has bonded than during the recruitment phase.

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[3] For men, this should be a non-feminised environment.

6.5.3   PPI activities

Suggestions to encourage parents to engage with, and advise on, the research included;

- Using local support groups for parents to encourage parent committee members or consult on research measures and research design.
- Dissemination of findings through a DVD made by parents for parents, encouraging parent committee members and research parents to organise their own dissemination events, organising a 'movie screening' event to present findings in a fun way, to include a photo or keepsake.
- Encouraging positive culture and acceptability for male involvement through health practitioners completing new birth visits (eg. health visitors and midwives) routinely including fathers in discussions about the birth and early days infant care management experiences.
- Work with local community members to provide information about the study in wider community settings (other than children's centres) occupied by fathers, e.g. sports clubs and jobs centres.

7. Discussion

The findings reported here are limited due to the small numbers (n=9) involved in the discussion groups, although in many ways, this facilitated rather than inhibited discussion. The attendance levels reflect general difficulties related to engagement, although in this instance three of the nine parents were fathers.

The participants were particularly engaged in the discussions, and provided some very useful insights into parent engagement, recruitment and programme attendance. Although the sample size was small, a diverse group of parents were represented including parents who had never attended parenting programmes as well as others who had been referred to them by social services. The sample also included three fathers – a group typically under-represented in parenting research. Those who had attended parent programmes could in many ways be seen as 'successes', especially in relation to their positivity about their experiences and their stories provide some valuable lessons.

Our discussants provided a number of clear recommendations for strengthening the overall research design. Those noted below will be included in the full research proposal and have also been costed in the research budget:

Recommendations:

- The research design needs to recognise the importance of local parents and carers talking face-to-face about their experiences to potential participants in order to enhance engagement and recruitment. We plan to trial this with fathers' groups in the pilot phase of the project;
- Accessibility and inclusivity are important. We will ensure that materials are accessible to a wide range of participants (taking into account literacy and first language) – they will be written in participant-friendly (as opposed to academic) language;
- Those initially engaging with parents for the research, such as children's centre staff, midwives, health visitors etc., should either be trained in, or at least have participated in, a parent programme taster session so they understand what it entails and who would most benefit from participation;

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- Researchers were seen as non-threatening and in some cases preferable as the initial point of contact, possibly due to the perception that they were (and would be) independent from the social or health services. Where possible, they should be engaged with the recruitment process;
- In order to retain parents allocated to control (service as usual), some continued form of contact such as a parent advice line was advised. The research team will consider the use of a 'parent hotline' during the proposed pilot or some form of linkage to family intervention services;
- It is important to be very clear about the role of the research, the commitment involved in participating in a research study *and* potentially a parenting programme. This includes managing the expectations of those not allocated to intervention or to a (IY-Infant or IY-Toddler) programme. This would involve clear briefings involving 'referrers' and researchers and promotional literature. The proposed parent advisory committee would be able to advise on the content of any such literature;
- When considering potential barriers to attendance barriers (eg. venue type, locality, transport, child care, timing of delivery etc.) individual circumstances should be taken into account *as well as* data generation comparability between research participants;
- Measures should be light-touch, user-friendly, and fully explained. Confidentiality and anonymity assurances should be carefully maintained throughout;
- A parent advisory committee should be set up to support the research and advise on engagement with participating parents, and one committee member should attend main research steering committee meetings;
- Length of time of data collection should be clear and involve minimal form-filling by participants; outcomes should be clearly communicated to participants. We will seek the views of the parent advisory committee on measures – particularly where comparable measures of the same domain (at similar cost) exist; and
- The venue for data collection should be guided by parental wishes – whether in the home or elsewhere, in a quiet environment where parent-child interaction can be observed.

In our less structured discussions with service staff, we found support for many of the parental suggestions and recommendations. These included, in particular:

- The need for a light-touch approach i.e. ensuring that parents had a number of 'fun' activities with their children, while getting to know the service staff members, prior to attempts to engage parents in any consultations. This would be particularly effective in establishing trust and ensuring that parents felt listened to.
- The importance of appropriate timing and location of parenting programmes to suit parents/carers. This would require flexibility in organising parenting sessions, and staff workloads.
- The need to ensure that service and programme delivery personnel have the appropriate skills to engage parents in different ways, to follow up parents' non-attendance, and to accommodate parents' individual needs and requirements.
- The willingness of parents to be engaged in advising on the research, perhaps linking to a wider parent support network, if available.
- Dissemination of the research to engage current and future parents in parenting programmes. The ways in which to do so should be fun and imaginative and engage both parents and their children. Word of mouth and empowerment of parents is of great importance.

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- Engaging and retaining parents with low literacy levels needs careful consideration in the research, particularly as the intervention families all receive an IY-I book, which is not currently available in any other format. Suggestions included reading the book and recording the content on to a CD, with additional simple handouts for activities which are included in the book.

Acknowledgements

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Appendix: Discussion group schedule

1. Recruitment to study/engagement

Q.1. What, if anything, would encourage you to take part in this study/parent programme? And what, if anything, would deter you from participating?

Prompts:
a) Who would you feel was most appropriate to ask you to participate? And is there a time that you would feel was best?
   - How would you feel about the health visitor asking you? A researcher? Is there anyone else you would feel this was an appropriate request from? Anyone who you feel would be inappropriate to discuss with?
   - In terms of timings, is there a time during the early period of your child's life, or even prior to the birth, would you think this request would be most appropriate? Is there a time when you would deem it as least welcome?
b) What kind of information would you require about the study in advance of agreeing to take part?
   - Information leaflet, phone line, etc?
c) What are your thoughts on random allocation?
   - How would you feel if you were assigned to control / intervention?

2. Retention of participants to parenting programmes

Q.2. If you were allocated to receive the parent programme, what, if anything, would encourage you to attend the classes?

Prompts:
a. Would there be any the barriers to your attendance?
   - If there are barriers how could they be overcome?
b. How, if at all, would the location affect your attendance? (geographical location and setting)
c. What about timings of groups? Is there any times of day that would be more or less convenient? For example currently classes are generally held during the school day, would this be helpful or problematic for you?
d. Would there be any differences in your answers above if you were allocated to one programme over the other, for example, would attendance for 22 weeks prove more difficult than 10 weeks? If Yes;
   - Why?
   - Are there any ways that would help overcome that?

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3. Retention to study and data collection

Q.3. We mentioned that this study involved a Randomised Controlled Trial (RCT) design, which means some people may be recruited received some form of parenting intervention, ie. they would receive a book only, a book and a 10 week baby parenting programme or the same book and a 22 week baby and toddler parenting programme, other's maybe allocated to being control parents which means they would receive the usual services offered to all parents. How would you feel about being allocated to one of those different groups or to the control group?

Prompts:
   a) Would your allocation impact on your participation in the study?
      o If yes, in what ways? What would impact your decision / what, if anything, would influence/change that decision?
   b) This is a copy of the book, which all intervention parents will receive. What are your first impressions of it?
      o Why?
      o Do you think you would read it? If so, why, if not, why not?

Q.4. All those participating in the study, whether control or parenting intervention, would be requested to provide information to researchers at regular intervals. All information gathered would use already established methods used with other parents and children in other research studies. At the moment we are proposing this to happen four times over the course of the study. The information would be collected by researchers and mainly look at children's social and emotional well-being but may include some measures about parent's well-being and parenting and may also access children's health records. Do you see any issues relating to this? If so, how may they be overcome?

Prompts:
   a) When / where would be the best times / place for this collection of information take place?
   b) How long would be a reasonable amount of time for your to spend with researchers at each time point?
   c) How, if at all, would your allocation influence your participation in this aspect of the research? For example, if you were a control parent how would you feel about this aspect of the research?
      o Is there anything that would influence this / affect your decision?
   d) Is there any information you may be reluctant to provide? Why? And what may influence you to provide it?
      o All information would remain confidential, does that influence your decision? Why & in what ways?
      o How would you feel about receiving a financial thank-you for your participation?

4. Next steps and public involvement in research

Q.5. What ways, if any, do you feel it would be useful for further public involvement in taking this proposal for research into the social and emotional well-being of under 2 year olds?

Prompts:

a) what areas, if any, do you think such involvement would be particularly important?
b) In what ways, if any, do you think you such participation could best be arranged?
  o Discussion group, email, on-line etc.?

Q.6. If we were successful if securing funding for this research what, if any, ongoing input and support would you like to see put in place?

Prompts:
a) In terms of the research conducted?
b) In terms of explaining and disseminating the findings of the research to parents, professionals and policy-makers?
c) How could this best be facilitated?

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