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**Article:**

Stuttard, Lucy, Clarke, Susan Evelyn, M, Thomas et al. (2015) Replacing home visits with telephone calls to support parents implementing a sleep management intervention: findings from a pilot study and implications for future research. *Child: Care, Health & Development*. ISSN: 1365-2214

<https://doi.org/10.1111/cch.12250>

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# **Replacing home visits with telephone calls to support parents implementing a sleep management intervention: findings from a pilot study and implications for future research**

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Running title: Sleep interventions: modes of parent support

Acknowledgements: The research reported here was commissioned by the Centre for Excellence and Outcomes (C4EO) with funding from the Department for Education (DfE). The views expressed are the authors' and do not necessarily reflect those of DfE. We would like to thank all the families who took the time to complete our research questionnaires and speak to us about their experiences.

This is the peer reviewed version of the following article: Stuttard, L., Clarke, S., Thomas, M. and Beresford, B. (forthcoming) Replacing home visits with telephone calls to support parents implementing a sleep management intervention: findings from a pilot study and implications for future research, *Child: care, health and development*, (Available online from 10 April 2015) which has been published in final form at <http://onlinelibrary.wiley.com/doi/10.1111/cch.12250/abstract>.

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## **Abstract**

*Background* Resource constraints may inhibit the provision of appropriate interventions for children with neurodisabilities presenting with behavioural sleep problems. Telephone calls (TC), as opposed to home visits (HV), may be a more resource efficient means of supporting these families.

*Objective* To conduct a preliminary investigation exploring the feasibility and acceptability of replacing HV with TCs to support parents implementing sleep management strategies, and to gather evidence to inform the design and methods of a full trial.

*Methods* Parents referred to a sleep management intervention routinely delivered by a community paediatric team were alternately allocated to receive implementation support via home visits (n=7) or telephone calls (n=8). Activity logs recorded the frequency, duration and mode of support. Parents and practitioners were interviewed about their experiences of receiving/delivering the intervention.

*Results* Intervention drop-out was low, the frequency, number of contacts and intervention duration appeared comparable. Parents allocated TC received less contact time. Parents valued implementation support irrespective of delivery mode and practitioners reported that despite initial reservations, implementation support via TC appeared to work well.

*Conclusions* Telephone calls appear an acceptable and convenient mode of delivering sleep support, valued by both parents and practitioners. We recommend effectiveness is investigated in a full-scale trial.

## **Introduction**

Sleep disturbances in children with disabilities are more common and severe compared to typically developing children (Tietze *et al.* 2012, Dorris *et al.* 2008). As with typically developing children, the origins are often behavioural, located in the way parents manage their child's sleep (Wiggs 2009, Newman *et al.* 2006, Stores and Stores 2013). Learning difficulties and communication impairments may hinder the establishment of appropriate sleep routines, and parents' expectations may be low, believing that sleep problems are 'part of' the child's impairment (Wiggs and Stores 2004). Once physiological/anatomical reasons for sleep disturbance are excluded, behavioural approaches, which seek to change parents' management of sleep-related problems, are advocated (Galland and Mitchell 2010, Bruni and Novelli 2010, NICE/SCIE 2013, Appleton and Gringras 2013).

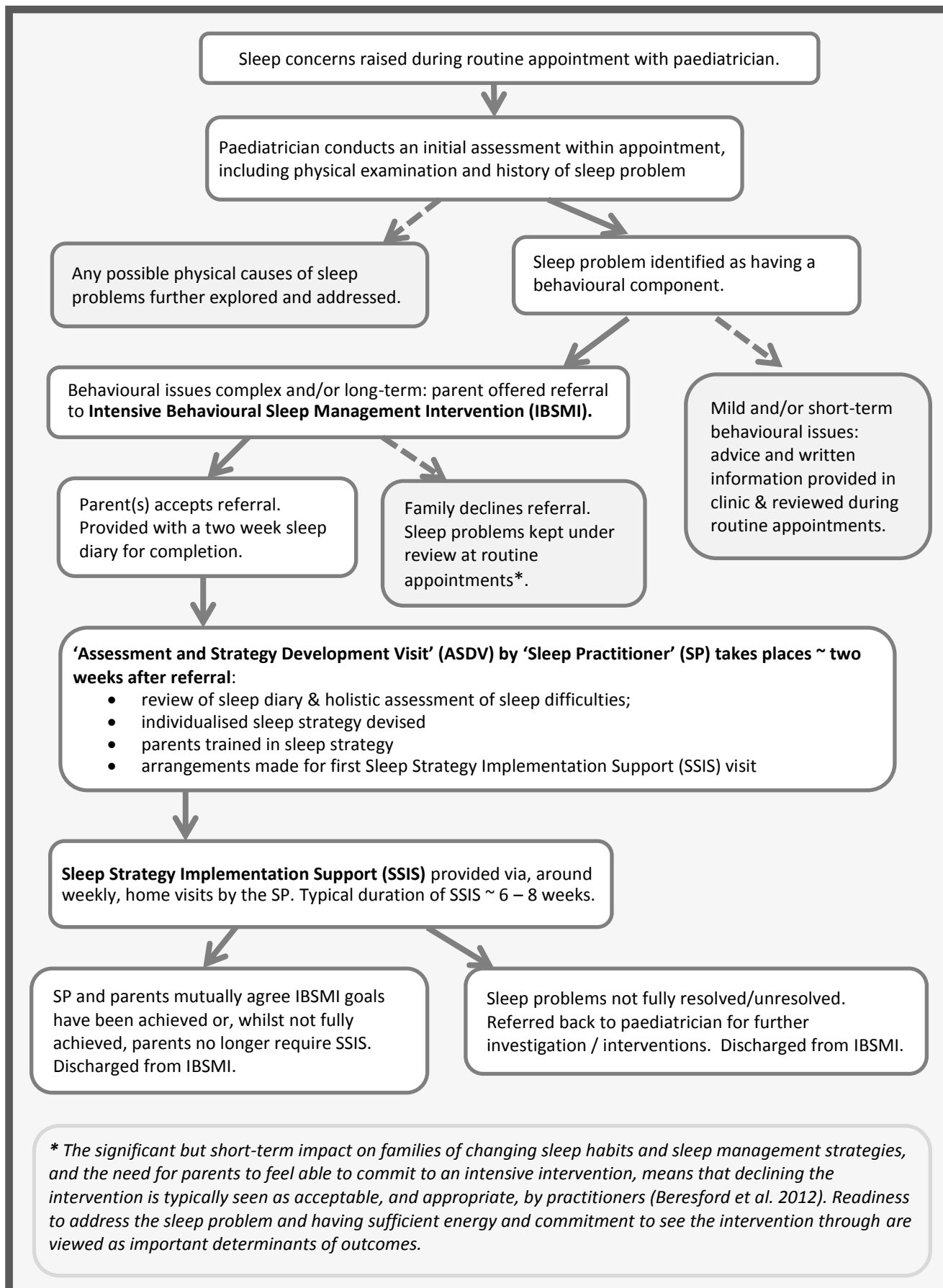
The intensity of a sleep management intervention depends on the complexity of the sleep problem and/or child/family-centred factors. Where they do not, or cannot, be resolved through low-intensity approaches (e.g. leaflets; advice during routine appointments), more tailored and

sustained approaches (referred to in this paper as intensive behavioural sleep management interventions (IBSMI)) are recommended (Bruni and Novelli 2010, NICE/SCIE 2013, Appleton and Gringras 2013). These involve a detailed assessment, the creation of an individualised behavioural sleep management strategy and time-limited, (typically) face-to-face support as parents implement the strategy. However, despite promising evidence regarding their effectiveness (Vriend *et al.* 2011, McDaid and Sloper 2009) these interventions are not routinely available (Montgomery *et al.* 2004). One reason for this is that they are perceived as too time-intensive: particularly the requirement to support parents as they implement the sleep management strategy (Montgomery *et al.* 2004). This barrier has been exacerbated by current resource/staffing constraints within the NHS. Instead, pharmacological approaches are used, though recent studies question their efficacy (Appleton and Gringras 2013).

The research reported here concerns the experiences of a Child Development Centre (CDC) which offers an intensive behavioural sleep management intervention (IBSMI) to families with young (aged 0-4 years) children with neurodisabilities (see Figure 1). Resource constraints were limiting the number of families offered this support with the sustainability of the service becoming increasingly fragile. The team decided to pilot the use of telephone calls, as opposed to home visits, to support families as they implemented their sleep management strategy. In order to independently evaluate the pilot, the CDC staff collaborated with a team of academic researchers.

Existing evidence on effectiveness, impact on practice, and families' experiences of using telephone calls, as opposed to home visits, to deliver sleep strategy implementation support (SSIS) is limited. Earlier studies investigating sleep support interventions using telephone contact have been in experimental settings (e.g. Wiggs and Stores 1998, Bartlet and Beaumont 1998). To date, there has not been any published work directly comparing the acceptability of telephone calls with (standard) face-to-face contact in routine practice.

**Figure 1. Overview of the CDC's sleep management pathway**



Study objectives were to:

- investigate the impact of mode of contact on the delivery of SSIS (e.g. contact frequency, duration of intervention);
- monitor deviations in mode of SSIS contact and intervention drop out;
- explore parents' experiences of SSIS, including a comparison between those receiving telephone calls vs. home visits;
- explore practitioners' experiences of working to the alternative modes of delivering SSIS;
- inform the design of an intervention protocol for a trial comparing home-visit vs. telephone call administered SSIS;
- collect and scrutinise preliminary data on outcomes.

This paper reports findings with regard to the first five objectives. Data on outcomes, and detail on the research methodology, is presented in a publicly available internal report (Beresford *et al.* 2012).

## Method

A mixed methods design was used (see Box 1). NHS Research Ethics Committee approval was secured (REC Reference Number 09/H1305/46). The study took place between November 2009 and September 2010.

### Box 1. Main elements of the study

- Parents recruited to the study alternately allocated to the study arms: Sleep Strategy Implementation Support (SSIS) via home visits (HV) vs. telephone calls (TC).
- For each case, the Sleep Practitioner (SP) recorded the delivery of the intervention using an 'Activity Log'.
- Semi-structured interviews explored parents' and practitioners' experiences of delivering/receiving the intervention.

## Recruitment

During the appointment in which parents accepted a referral to the IBSMI, participation in the study was discussed. Interested parties received a research pack containing: a project information sheet and data collection instruments (socio-demographic and health questionnaire, outcome measures). Initial agreement to participate was obtained during this appointment and at this point parents were alternately allocated to receive either telephone calls or home visits. Written consent was obtained at the Assessment and Strategy Development Visit (see Figure 1).

## **Activity Logs**

A specialist health visitor was the CDC's 'Sleep Practitioner' (SP) at the time of the pilot. The SP recorded all contacts with parents including: mode, location, duration, reasons for: deviation from allocated mode of contact, and missed or cancelled appointments.

## **Semi-structured interviews with parents and practitioners**

A sub-sample of parents were invited to take part in a semi-structured telephone interview two-to-three months' post-intervention (range 6-17 weeks). The sample represented children of different ages, diagnoses, and extent to which parent-set sleep goals had been achieved by the intervention. In addition, the paediatrician who had overseen the development and implementation of the sleep management pathway and the sleep practitioner (SP) were interviewed about their perceptions and experiences of the alternative modes of delivering SSIS. Interviews were analysed using thematic qualitative analysis techniques (Miles *et al.* 2013), specifically the Framework approach (Ritchie and Lewis 2003). Parent and practitioner interviews were analysed separately, followed, where relevant, by a comparison of views in terms of commonalities and differences.

## **Results**

### **Sample**

Thirty families were offered an IBSMI during the study period, of which 18 accepted. This represented the typical take-up rate. Restricted staff availability resulted in 3/18 families not receiving the intervention during the study period. The remaining families were allocated to receive either home visits (HV; n=7) or telephone calls (TC; n=8). No-one refused allocation. Mothers were the primary recipients of the intervention, although fathers were sometimes present.

Demographic/health data was provided by thirteen parents. The children represented were aged 1-4 years old (M=2.77, SD=.927), and all had neurodisabilities. Parent-reported diagnoses included cerebral palsy, metabolic disorders, developmental delay, sensory impairments and/or autism. Six children were reported as having a learning disability. The majority (n=11) were boys. All parents reported the sleep problem had endured for at least six months and, for seven children, had been present for over a year. All mothers were white British and two were lone parents. A sub-sample of eight mothers (children aged 1-4 years, mean=2.5 years, SD=2.07) participated in a semi-structured interview (HV: n=4; TC: n=4).

### Impact of SSIS mode of contact on intervention drop-out

One parent (HV) dropped out of the intervention prematurely, postponing the intervention indefinitely following the ASDV. For the remaining families, the intervention continued until a time mutually agreed between the sleep practitioner and parent(s). For 10/14 families no further work on sleep management was perceived to be required. The remaining four families (HV:  $n=1$ , TC:  $n=3$ ) were referred back to the paediatrician for additional sleep-related intervention(s), including pharmacology.

### Impact of mode of contact on delivery of SSIS

Families received between three and seven SSIS contacts (Table 1). Apart from one family who postponed the intervention for six months due to family illness (HV), the duration of intervention was similar (HV: 3-9 weeks; TC: 3-10 weeks). On average, parents receiving home visits received an extra forty minutes of contact time with the SP compared to parents receiving telephone calls. This was because home visits typically took longer than telephone contacts (home visits lasted between 30 minutes and one hour, whereas telephone calls took between 10 and 30 minutes). Consequently, average SSIS contacts in the TC group were shorter (Table 1).

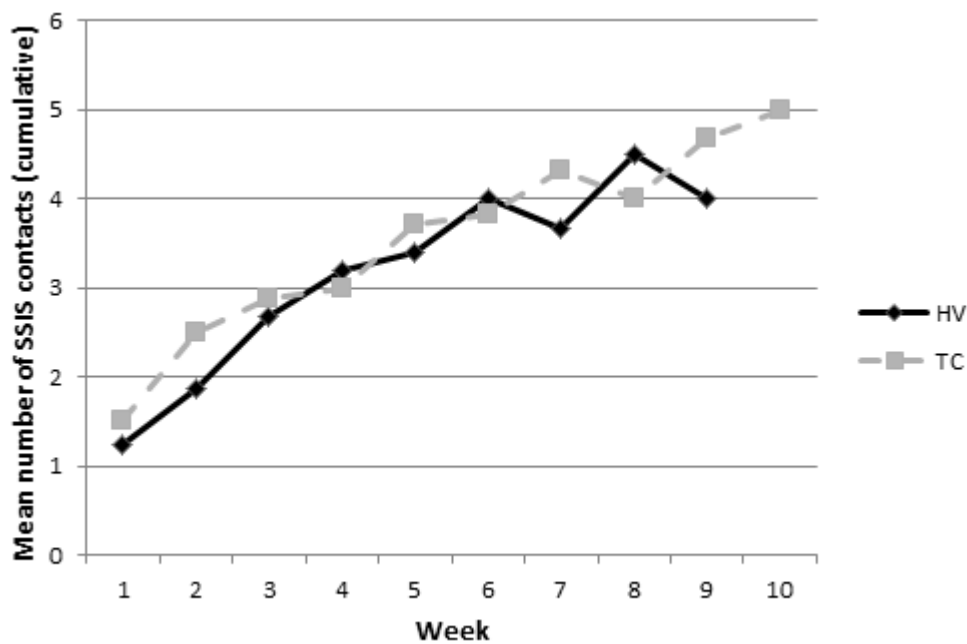
**Table 1: Delivery of Sleep Strategy Intervention Support (SSIS): HV vs. TC**

SSIS contact mode	Duration in weeks Mean (SD, 95% CI)	Total contacts Mean (SD, 95% CI)	Average contact time in minutes per SSIS contact Mean (SD, 95% CI)*	Average total contact time in minutes Mean (SD, 95% CI)
Home Visit (HV)	6.5 (2.07, 4.32-8.68)	4.43 (1.27,3.25-5.61)	32.08 (13.82, 26.55-37.61)	165.71 (44.10, 133.04-198.39)
Telephone Call (TC)	7.25 (2.31, 5.31-9.19)	4.88 (1.36, 3.74-6.01)	20.86 (5.65, 15.21-26.51)	122.50 (48.84, 88.69-156.35)

\*Occasionally, deviations from the contact mode allocated occurred. These figures are a representation of the average contact appointment time for *all* appointments that occurred within each group, regardless of whether they corresponded to the allocated mode.

The expectation is that SSIS occurs on around a weekly basis (Figure 1). Difficulties contacting parents and cancelled appointments resulted in irregular appointment schedules. Figure 2 presents the mean cumulative contacts for the number of parents still receiving the IBSMI week on week. Overall, the pattern of SSIS was similar for each contact mode. Initially, contact typically adhered to the intervention protocol with, on average just over one SSIS contact per week. However, by Week 3 the interval between contacts had increased with this pattern continuing until the intervention concluded. A longer intervention period was usually a consequence of less frequent contacts. Parents receiving SSIS over nine weeks typically received just one more SSIS contact than parents where SSIS lasted five weeks.

**Figure 2. Frequency of SSIS contacts with the Sleep Practitioner**



**Adherence to mode of contact**

For parents allocated to receive HV, 7/31 contacts were via telephone (Table 2). In five instances, these were at the request of the parent, in the remaining two instances, due to time constraints, the sleep practitioner telephoned the parent rather than making a home visit. In addition, one SSIS appointment took place at the CDC as opposed to the family home. For parents allocated to receive TC, 7/39 SSIS contacts were face-to-face. On three occasions this was because the sleep practitioner felt complex, family-centred issues needed to be discussed face-to-face. The remaining four face-to-face contacts took place at the CDC because the parent was already attending for other reasons.

**Table 2: Mode of contact: adherence to mode allocated**

SSIS contact mode	Number of SSIS contacts as allocated (%)
Home Visit	23/31 (74%)
Telephone Call	32/39 (82%)

**Parents’ views on the acceptability of the different modes of SSIS contact**

Parents believed on-going contact with the sleep practitioner, whether via TC or HV, as they implemented sleep management strategies kept them committed and motivated, and served to maintain their understanding of behavioural approaches to sleep management. Parents reported

being satisfied with the mode of SSIS they had received and believed it was an effective way of providing implementation support.

It's a great service ... it's a point of contact for reassurance and keeps bringing you back to the importance of consistency, of maintaining a routine, it keeps that fresh in your mind. [Mother of a three year old boy with autism, TC]

Parents consistently commented on, and valued, the flexibility of the intervention. All believed that the bespoke nature of the intervention was a key factor behind the improvements in their child's sleep which they had experienced.

It [the initial assessment] felt personal to the family, not just something from a book. [Mother of a one year old boy with Cerebral Palsy, HV]

Those who had received SSIS via TC appreciated this as less intrusive and time-consuming. This was particularly valued given that many parents had multiple appointments regarding their child. It was seen as a quick and effective way to receive feedback and advice. However, one parent mentioned that a telephone call felt less personal than a home visit and may mean the SP has 'less of a feel' of the child's sleep problems and how the family were managing them.

Finally, parents reported that whilst telephone contact was acceptable as they implemented sleep management strategies, they believed the initial home visit (ASDV) was crucial and could not be replicated, or work as well, over the telephone.

### **Practitioners' experiences of delivering the intervention using alternative modes of SSIS**

Both practitioners believed that SSIS was a core and vital element of the intervention:

The continued support, I think, is vital...it's that support ... just keeps parents going really when they would like to just give up. (Paediatrician)

The sleep practitioner, who had been involved in delivering this intervention for a number of years, recalled feeling concerned about replacing face-to-face SSIS with telephone calls. However, these concerns had not been realised.

I haven't ever felt .... "This isn't working over the phone, I need to go and see them at home". That hasn't been the case. (SP)

Furthermore, advantages to telephone-delivered SSIS were identified, particularly in terms of being able to be more flexible and responsive to an individual family's needs. Thus, whilst weekly SSIS contacts were, on the whole, felt to work well, increasing the frequency of contacts, when necessary, was more feasible when support was being delivered via telephone calls rather than home visits.

On some occasions I've felt that they might benefit ...from an earlier phone call. So I might have left them, say, with something on a Friday and maybe rung them on a Monday or a Tuesday rather than, like, the next week, if you see what I mean. (SP)

## **Discussion**

The research reported here investigated the introduction of an alternative mode to providing sleep strategy implementation support (SSIS) to parents of young children with neurodisabilities receiving an intensive behavioural sleep management intervention. It explored the impact of using telephone calls in place of home visits on the delivery of SSIS, intervention drop-out and duration, and parents and practitioners' experiences. A further objective was to inform the development of an intervention protocol for a trial comparing these alternative modes of delivering SSIS. A growing interest and commitment to developing a robust evidence-base on sleep management interventions for children with neurodisabilities (National Institute for Health Research 2014) makes the findings and reflections set out in this paper timely and pertinent.

Evidence regarding the acceptability of telephone calls (TC) to deliver SSIS was consistently positive. Mode of SSIS was not found to elicit strong views, no parent requested that they received their support via a particular mode or reported any negative experiences. Indeed several advantages to providing SSIS via TC were identified including convenience and timeliness of support and advice. These views were resonated by the sleep practitioner who, despite initial apprehension regarding using TC to deliver SSIS, reported it to work well, affording greater flexibility and responsiveness in the way she could support families. Telephone calls also freed up SP time that would have been spent travelling. There was also no evidence indicating that SSIS via TC led to parents being more likely to drop-out of the intervention.

As would be expected, the frequency of SSIS contacts and duration of SSIS was not fixed. A characteristic of complex interventions is that they are responsive to individual needs and circumstances (Craig *et al.* 2008) and this is reflected in the intervention protocol (Figure 1) which stipulates SSIS should be delivered at 'around weekly' intervals and for approximately 6 to 8 weeks. Whilst sample sizes were too small to examine quantitatively, the perception of the SP was that TC offered her greater flexibility than HV and allowed her to offer support in a more timely way.

One of the purposes of this pilot was to inform the design of a trial comparing the two modes of SSIS. These findings raise questions in terms of the flexibility of the intervention protocol: e.g. intervals between SSIS contacts, and the number of contacts. Our view is that to restrict the responsiveness of SSIS would not reflect actual practice nor would it properly test how the mode of providing SSIS affects *the way* the intervention is delivered. Individual circumstances and preferences may further moderate the acceptability and effectiveness of each mode. Whilst the intervention is regarded as non-clinic based, occasionally SSIS contacts took place at the CDC, usually because it was more convenient for the parent. Minimising the burden on families was the most common reason that SSIS contacts allocated to be home visits were occasionally delivered via telephone. Likewise, on the occasions that the SP visited a family who had been allocated telephone calls this was due to an acute issue which the SP had to deal with in fulfilment of her wider role with the family. All the issues discussed above highlight the delicate trade-off there is to be had between a pragmatic trial which closely reflects the practice/settings in which this intervention is delivered, to 'muddying' the intervention arms so much that they are indistinguishable. The number of parents who return to the paediatrician for further sleep support following the termination of SSIS, should also be explored.

## Conclusions

These preliminary findings indicate that it may be acceptable to support parents implementing a behavioural sleep intervention via telephone calls opposed to face-to-face. Where this approach is considered, we would recommend that practitioners are mindful of the perceived importance of the initial home visit which all families received and to allow for some flexibility where further face-to-face contacts may be beneficial. Taking into consideration the issues described, we would argue that a larger multi-centre pragmatic, randomised controlled trial, including a cost-effectiveness evaluation, is an important next step. The significant resource constraints that services operate under, the desire within health services to identify effective and cost-effective alternatives to delivering interventions, and evidence of the impact (on families, services and society e.g. Tietze *et al.* 2014, Simola *et al.* 2014, Quach *et al.* 2013, Hillman *et al.* 2006) of not addressing sleep problems all serve to add weight to the argument for further research.

### Key messages

- There is promising evidence that intensive behavioural sleep management interventions are effective at supporting families whose children have complex and severe behavioural sleep problems, however, their delivery is hindered by resource constraints.
- This study found that telephone calls to support parents whilst they implement a bespoke

sleep strategy may be an acceptable alternative to home visits.

- Several advantages were observed of providing support in this way, including: resource (time) savings, increased flexibility and reduced intrusiveness for families.
- A fully powered RCT is recommended to evaluate the effectiveness and costs of providing sleep strategy implementation support via telephone calls as opposed to home visits.

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