

This is a repository copy of *Parents' experiences of psychoeducational sleep management interventions: a qualitative study of parents of children with neurodisabilities*.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/102296/>

Version: Accepted Version

Article:

Beresford, Bryony Anne orcid.org/0000-0003-0716-2902, Stuttard, Lucy orcid.org/0000-0001-7205-7151, Clarke, Sue et al. (1 more author) (2016) Parents' experiences of psychoeducational sleep management interventions: a qualitative study of parents of children with neurodisabilities. *Clinical Practice in Pediatric Psychology*. pp. 164-175. ISSN 2169-4834

<https://doi.org/10.1037/cpp0000144>

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

Parents' experiences of psychoeducational sleep management interventions: a qualitative study of parents of children with neurodevelopmental disabilities

Bryony Beresford

Social Policy Research Unit

University of York

Lucy Stuttard

Social Policy Research Unit

University of York

Susan Clarke

Social Policy Research Unit

University of York

Jane Maddison

Social Policy Research Unit

University of York

*Author for correspondence

Author contact details:

Email: bryony.beresford@york.ac.uk

Postal: Social Policy Research Unit, University of York, York, YO10 5DD. UK

Abstract

Psychoeducational approaches to managing behavioural sleep problems in children with neurodisabilities are directed at the parent, increasing their knowledge and understanding of sleep and requiring them to change the way they manage sleep disturbance. Given parental engagement with and adherence to an intervention are critical to its success, it is important we understand parents' experiences of participating in interventions of this nature. It is surprising therefore that, to date, research in this area is extremely limited. This paper reports the findings from a qualitative study of 35 parents who had received a psychoeducational sleep management intervention delivered through one of the following modes: a half-day workshop (n=8); a four session group-delivered intervention (n=15); one-to-one work with a specialist sleep practitioner (n=12). The study was part of a larger programme of work evaluating sleep management interventions for children with developmental disorders and/or autistic spectrum conditions. Purposeful sampling was used to represent: intervention outcome, child's diagnosis, parents' education, and partner involvement in the intervention. Focus groups and individual interviews were used to gather data. The data were subject to a thematic analysis in relation to: a) parents' descriptions of the processes by which a sleep management intervention (SMI) leads to improvements in their child's sleep; b) parents' views of the factors which hinder the achievement of positive intervention outcomes; and c) parents' views on intervention intensity and mode of delivery. The implications of the findings in terms the design, content and delivery of such interventions are discussed.

Keywords: sleep management interventions; parents; neurodisability; qualitative

Introduction

Sleep difficulties in children with neurodisabilities¹ (ND) are more common and more severe compared to typically developing children (Tietze et al., 2012; Dorris et al., 2008). They are associated with poor outcome for parents (e.g. heightened levels of parental stress and irritability, Wiggs, 2007; Teitze et al., 2012) and children (e.g. poorer educational progress and daytime behaviour problems, Simola et al., 2014). These outcomes increase demands on statutory services as well as creating further, additional support needs, such as respite care (McConkey et al., 2011; Quach et al., 2013). Parents consistently highlight the need for support with their child's sleep problems (Allard et al., 2014) although, historically, little time has been allocated to training the relevant professionals to provide this kind of support (Stores, 1999).

Existing evidence on the effectiveness of psychoeducational approaches to managing sleep disturbance in children with ND is weak but promising. Current guidance advocates that once clinical (e.g. pain, seizures) or respiratory reasons for sleep disturbance are excluded, behavioural, or psychoeducational, approaches should be tried before pharmacological interventions are considered (eg. Galland and Mitchell 2010, Bruni and Novelli 2010, Vriend et al., 2011). Such interventions seek to improve parents' understanding of sleep and change the way they manage sleep disturbance. The justification for this is that, in common with typically developing children, the origins of sleep difficulties for many children with neurodevelopmental disabilities are behavioural, located in the way parents address and manage their child's sleep (Wiggs 2009, Newman et al. 2006, Stores and Stores 2012).

The intensity of psychoeducational interventions depends on the complexity of the sleep problem and/or child/family-centred factors. The provision of written or verbal information

or advice within a routine appointment may be sufficient to pre-empt or manage the early emergence of sleep disturbance. For more complex or long-standing cases, and/or where parents have wider support needs, the intensity of the intervention may need to increase (in terms of, for example, amount of contact time with a practitioner, the depth of the assessment, the creation of child/family-specific sleep management strategies). It may also include time-limited support as parents implement a sleep management strategy. In recent years there has also been an increasing interest in using groups, as opposed to a series of one-to-one sessions, to deliver sleep management interventions (SMIs) (Stuttard et al., 2015a).

A fundamental feature of the psychoeducational approach is that the intervention is directed at improving or changing parents' understanding of sleep and the strategies used to manage their child's sleep. Parental engagement with and adherence to the intervention is critical to achieving a positive outcome. Understanding parents' views and experiences of SMIs thus has the potential to improve the content and delivery of these interventions and their effectiveness. It is surprising therefore that research exploring parents' experiences of such interventions is extremely limited (Nikolopoulou and St-James-Roberts, 2003). Indeed, the authors have identified just one study has been identified which investigated this issue (Tse and Hall, 2007).

Tse and Hall (2007) explored the views and experiences of parents of typically developing infants aged 6 to 12 months who had received an SMI, including aspects of the intervention which were perceived to be associated with positive outcomes, and the challenges associated with changing the way they managed their baby's sleep. A greater understanding of sleep rhythms/cycles and the importance of routine and developing self-settling skills were commonly reported as important learning points. Furthermore, parents valued input which

enabled them to implement specific strategies, broken down, where necessary, into feasible steps or stages. In terms of the challenges of implementing new sleep management strategies, parents reported difficulties with persevering with new strategies or adhering to new routines, other caregivers undermining the intervention, and concerns about disturbing neighbours during the night. Finally, Tse and Hall (2007) note that parents identified increased, or regained, confidence as parents as a positive, but unanticipated, outcome.

The findings reported in this paper develop this evidence base in two broad ways. First, it reports the experiences of parents of pre- and school-aged children with neurodevelopmental disabilities. Second, it explores and compares experiences of SMI's of different intensity and mode of delivery.

Method

The data reported are drawn from a larger programme of research which evaluated four psychoeducational sleep management interventions (SMIs) for parents of pre-school and school-aged children with neurodisabilities. Each intervention was subject to an outcomes and process evaluation. Findings of the outcomes evaluations are reported elsewhere ((Stuttard et al., 2015a; 2015b). The process evaluation element investigated the experiences of delivering, or receiving and implementing, an SMI and comprised interviews with practitioners and parents. This paper reports the findings from the interviews with parents.

The SMIs under investigation were all being routinely delivered, either by a community paediatric or child mental health team in England, to children with ND, see Figure 1. Each SMI was being delivered in a different locality, rather than being parts of a tiered approach to the management of sleep disturbance within a single locality or region. All these services

worked routinely with children with ND and the practitioners delivering the SMIs had received specialist training on delivering sleep management interventions to this group of children.

FIGURE 1 HERE

The SMIs varied in terms of the *intensity of support* (ie. extent of one-to-one work, degree to which intervention is individualised to specific case, and support offered to parents as they implemented new sleep management strategies). *Mode of intervention delivery* mapped on to the intervention intensity, with the less intensive interventions (C and D) being delivered via groups. In addition, for Intervention A, parents varied in terms of the mode of implementation support (via home visits or telephone calls) they received.

Sampling

Parents participating in the outcomes evaluations of the SMIs (n=74) formed the sampling pool for the process evaluation. A purposive sampling strategy was used in order that the process evaluation sample represented a range of intervention outcomes and socio-demographic factors. In terms of intervention outcomes, data collected by the outcomes evaluation on progress towards achieving parent-set goals for their child's sleep (collected pre- and post-intervention and 12 weeks follow-up) was used. In addition, representation of the following socio-demographic factors was sought during sampling: parents' gender, employment status, preferred language, school leaving qualifications, nature of the child's disability, and whether the parent attended the intervention with their partner. For Intervention C, parents were recruited across four deliveries of the intervention and for Intervention D, across 5 deliveries.

Recruitment

The purposive sampling frame (see section above) was used to identify parents to approach to take part in the process evaluation, with a target sample of 8-10 parents per intervention.

Parents were approached regarding participation in the study via a letter which enclosed a study information leaflet. The letter was followed up by a telephone call from a member of the team to discuss participation and, if they agreed, to arrange a suitable time and date for the interview. For Intervention C (a 4 session, group-delivered intervention), an opportunity to conduct a focus group discussion was offered by the clinical lead of the service delivering the intervention. The focus group interview was held following the final session of a delivery of the intervention. Parents were given letters of invitation and study information leaflet at the penultimate session. Those willing to join the study stayed on after the final session of the intervention to participate in the focus group. Written consent was obtained before the start of the interview / focus group.

Data collection

Individual semi-structured interviews, conducted via telephone calls, were used. In addition, a focus group with parents who had received one of the deliveries of Intervention C was carried out. Fieldwork was carried out by three members of the research team. Individual interviews lasted 30 to 60 minutes. The focus group, facilitated by two researchers, lasted 75 minutes. The topic guide used for the interviews and focus group covered the same topics including: factors affecting engagement and drop-out, views about the intervention in terms of content and mode of delivery, perceived outcomes, and factors identified as impacting on outcomes. Interviews and focus groups were, with participants' permission, audio-recorded. The focus group was fully transcribed. Depending on the complexity of individual interviews,

verbatim transcripts or detailed notes were produced. Fieldwork took place between July 2010 and February 2011. Parents had received the SMI, on average, 18 weeks previously.

Data analysis

A thematic approach (Miles and Huberman, 1999) was taken to data analysis, and adopted the well-established Framework approach (Ritchie, Spencer and O'Connor, 2003). The key questions driving the analysis were: what is the process by which changes in parents' sleep management strategies and children's sleep are achieved; what are the factors which hinder positive intervention outcomes; and what were parents' views of the mode of intervention delivery they received? Three researchers closely read all the interview data and worked together to agree key topics and emerging themes. From this, a series of thematic 'charts' were created in Excel in which each column denoted a separate sub topic or theme and each row an individual respondent. One researcher then extracted data from the transcripts/notes and onto the charts. The extracted data took the form of a summary and/or verbatim text. All data entered onto a chart carried a reference to its location in the raw data (ie. page number). In order to ensure a consistent and comprehensive approach to data extraction, a quarter of the interviews were subject to a second round of data extraction by a different member of the research team. The research team then met to check and review data extraction. Once data extraction was complete, one researcher led on a process of scrutinising the charts, making detailed analytical notes and observations which were then shared and discussed with the research team. An iterative process of refining these writings continued until the team was satisfied that the data had been fully analysed and comprehensively reported.

The sample

Thirty-five parents were recruited to the study. Twenty-eight participated in an individual interview and seven in a focus group, see Table 1.

TABLE 1 HERE

For each SMI, the parents recruited differed in terms of the extent to which they had achieved the sleep-specific goal(s) they had set at the outset of the intervention. None of the parents recruited to the study reported a deterioration, but some reported little change or progress: see Table 2.

TABLE 2 HERE

The socio-demographic and disability characteristics represented in the sample are set out in Table 3.

TABLE 3 HERE

Findings

We report the study findings around three broad topic areas regarding parents' views on:

- The processes by which sleep management interventions (SMI) led to improved sleep
- Factors hindering the achievement of improvements in the child's sleep
- Parents' views on intervention intensity and mode of delivery

The Processes by which Sleep Management Interventions (SMI) led to Improved Sleep

All the parents who reported some improvement in their child's sleep believed the SMI had contributed to this outcome. Positive outcomes were regarded as having been achieved through a set of separate, but linked and broadly chronological, intermediate outcomes:

- Affirmation of parents' existing knowledge and behaviour;
- Changes in parents' knowledge, understanding and attitudes;
- Changes in parents' sleep management behaviours.

Affirmation of parents' existing knowledge and behaviour.

Faced with the complexities of sleep problems and a child with a neurodevelopmental disability, parents found it reassuring to have confirmation from the practitioners running their SMI that at least some of what they had already put in place (for example, a good bedtime routine) was 'right' and should continue. Such reassurance gave parents the confidence to carry on with these positive strategies, as one parent explained:

I needed that reassurance ... "You are doing everything right, just persevere". I needed that, like somebody to tell me, "Yes, you are doing right" ... cos sometimes I thought well I must be doing something wrong. [78 (Mother) B]²

Even parents who did not report positive outcomes from the SMI still described the experience of having (some of) their current sleep management strategies confirmed as being correct by a sleep practitioner to be very pleasing and reassuring.

Changes in parents' knowledge, understanding and attitudes.

Parents identified a variety of ways in which new knowledge and understanding in relation to sleep had been beneficial. The broad dimensions of this learning were:

- the realisation that other families have sleep problems;
- increased understanding of sleep and sleep management;
- clarifying links between the child's condition and sleep problems.

While parents in the one-to-one interventions (A, B) were reliant on their sleep practitioner for new information, those in the group-based and workshop interventions (C, D) reported

learning from both the group facilitators and other parents. The acquisition of this new knowledge and understanding was typically presented as being a crucial step to progress being made in managing their child's sleep. It was also enmeshed within parents' accounts of positive changes in their attitude towards their child's sleep problem. Taken together, these changes in understanding and attitude appear to pave the way for the new or adjusted parent behaviours which, in turn, led to improvements in the child's sleep. The following sections provide further detail on each of these changes:

The realisation that other families have sleep problems.

Many parents spoke about the significance of becoming aware that they were not the only family with sleep problems. No longer perceiving their situation as unique served to reassure parents that their problems had not arisen through their own 'failure' as parents. Parents reported this helped them feel more confident that they were capable of making positive change. With respect to this, parents receiving group-delivered SMIs (C and D) talked about the value of hearing other parents' experiences directly:

It makes you more confident just because you know in that group that there are other people going through exactly what you're going through. [94 (Mother) C]

... being able to talk to the other parents and know that you're not alone, that you're not being a bad parent, that everyone's having difficulties. [97 (Mother) D]

Increased understanding about sleep and sleep management.

Greater understanding of the importance, and components, of a good bedtime routine emerged as an important outcome for many parents. For some, this was new knowledge, while others realised that their existing routine was not as good as they had thought. Parents in the SMIs delivered over a number of weeks (A, B, and C) had the opportunity to complete

a sleep diary and several commented on its value for pinpointing where they needed to make changes.

It did kind of hit home to me where it was going wrong. I quite enjoyed doing that [the sleep diary] because it gave me something to reflect back on, you know.

[80 (Mother) B]

For some, gaining what one mother called a better “*theoretical understanding*” [99 (Mother) D] of sleep was regarded as valuable in helping them to re-evaluate their child’s behaviours at bedtime and during the night. In some instances, this new learning did not prompt a change in the way bedtimes or night waking were managed; rather it reassured and allowed them to accept, or tolerate, their child’s sleep, or way of falling sleep, which previously had made them anxious or feel inadequate:

... as long as she’s relaxed and she’s not distressed and I know that she will fall asleep ... I think I’m a lot calmer with her. [97 (Mother) D]

I can’t even describe the devastation he does in his bedroom and then, at some point, he must pull his mattress off the bed and put it over the top of the devastation and go to sleep. I know before that course I would have been so stressed: “What a terrible mum I am letting him sleep like that!” Now, I think, “He’s asleep!” ... [91 (Mother) C]

Clarifying links between the child’s condition and sleep problems.

Many parents reported feeling unsure whether they should implement sleep management strategies they used with their typically developing children with their child with a neurodevelopmental disability. They reported that the SMI had helped them to understand the ways in which their child’s condition might always affect his or her sleep, the improvements in the child’s sleep which might be possible, and at what pace to expect change. This was a particularly dominant theme among parents of children with autism:

... and so really they [sleep practitioners] just confirmed that it was okay because they're different ... so it's okay for them to do different things and come on more slowly. [90 (Mother) C]

I'm not a bad parent; I've just had a different child to deal with. [81 (Mother) C]

Changes in parents' sleep management behaviours and strategies.

Across all four SMIs, parents gave many examples of how they had changed their behaviour as a result of attending an SMI, and with at least some success. It was also clear from parents' accounts that taking the step of receiving/attending an SMI had, in itself, provided an impetus to take action by increasing their resolve to tackle their child's sleep. There were two key areas of change in parents' sleep management behaviours: setting up or improving their child's bedtime routine, and handling night wakings. Across both areas, learning to persevere was cited as critical important (since progress could be slow), as was the support from others who cared for the child.

Some parents reported having learned about the importance of bedtime routine from the SMI, while others learned ways of improving their existing routine and/or valued the learning on the importance of consistency. The advice from practitioners - and for group delivered interventions the ideas and suggestions also from parents - on strategies to improve bedtime routines or improve communication with the child about the routine were valued highly. Most parents acknowledged experiencing times when they were tempted to abandon a new bedtime routine "*for an easy life*" [75 (Mother) A]. Parents in SMIs delivered over a number of weeks (A, B, and C) spoke about the value of ongoing support to help parents persevere with new or changed routines.

I did need help to keep sticking to it. It hit home that I needed to just keep going with it and stick to a routine in order to get somewhere. [80 (Mother) B]

Parents experiencing improvements with night waking reported that the SMI taught them to handle this situation differently, offering, at most, minimal and neutral attention. This had not always been easy, especially early on when parents confessed to feeling they were “*being horrible*” [76 (Mother) A] and/or said felt sorry for their child owing to their wider problems: *I think I’d just kind of give in a little bit more because of his condition* [80 (Mother) B].

Implementing such strategies did work for these parents although, as one parent noted, it took “*time, effort & patience*” [76 (Mother) A]. As with implementing a different bedtime routine, parents in SMIs delivered over a number of weeks valued the support the SMI provided to persevere with new sleep management strategies. Several parents also mentioned that keeping a sleep diary had helped to keep them motivated by revealing progress over time, however small, as in this example:

I felt I was achieving something and that I wasn’t awake all night. And when you start realising it’s not as bad, it starts improving quicker. [81 (Mother) C]

Importantly, as their child’s sleep problems began to improve, parents reported improvements in their own well-being through getting better sleep themselves. Parents noted that this, in turn, enabled them to have more energy and mental resources to further implement changes in sleep management.

Factors Hindering the Achievement of Improvements in the Child’s Sleep

There was a high level of consistency across parents’ accounts in terms of the factors perceived as hindering the achievement, or maintenance, of improvements in their child’s sleep. They can be organised under a number of themes:

- inadequacies in the educational element of the sleep management intervention
- impairment / disability-centred factors
- the demands the intervention places on parents/caregivers
- externally imposed disruptions or barriers

Inadequacies in the educational element of the sleep management intervention.

Parents who reported no improvements in their child's sleep often attributed this to advice received during the SMI not being appropriate to their child's needs and abilities. This experience was most frequently referred to by parents attending the half-day workshop (Intervention D), the audience and format of which did not allow the facilitators to address the way autism-specific issues might affect sleep management strategies. We return to this issue in a later section on mode and intensity of intervention delivery.

Impairment- / disability-centred factors.

Periods of ill-health.

Several parents spoke about relapses in the child's sleep when their child was undergoing medical interventions or otherwise unwell for a while, when "*everything goes out of the window*" [75 (Mother) A]. Parents believed the illness in itself may disturb the child's sleep and/or an already anxious child could feel more stressed and so less able to self-settle.

Diagnosis of autism.

Parents of children with a diagnosis of autism believed this was a barrier to successfully tackling their child's sleep difficulties. Specifically, they identified there may be co-occurring non-behavioural causes (eg. hyperactivity) and/or that features of autism itself (such as, heightened levels of anxiety, an inability to communicate, heightened sensitivity to

sensory stimulation) added to the complexity of implementing behavioural sleep management strategies. Typically, however, most parents said they had valued the SMI they had received and many appeared pragmatic about the limits posed by their child's difficulties.

The demands the intervention places on parent/caregivers.

Difficulties in changing or sustaining new sleep management strategies.

Parents encountered various difficulties in changing their sleep management behaviours and/or sustaining that change. First, the pace and complexity of everyday life could make it difficult to sustain their attention and energy on changing the way they managed their child's sleep, and/or prioritise this aspect of their child's life. Second, parents said that on days when they felt especially tired it was more difficult to maintain optimum behaviours with regard to sleep management. Third, some parents said they struggled to change their behaviour, especially in the face of strong resistance (distress) from the child. For example, one mother described her early work with a sleep practitioner as “*heart-wrenching*” as she tried to implement strategies for her son to sleep in his own room [76 (Mother) A].

The importance of consistency across caregivers.

The importance of consistency of sleep management strategies across all the child's caregivers was remarked on by a number of parents. Typically, parents who received the sleep management intervention had to ‘up-skill’ and encourage other adults (eg. resident and non-resident fathers, grandparents) who were involved in bedtime routines and/or management of night wakings to adopt new sleep management strategies. Among the parents we interviewed were both those who had been successful in achieving this and others who had encountered resistance or ‘under-commitment’ to what the parent was trying to achieve.

Externally imposed disruptions or barriers.

Changes and disruptions in usual routines.

Temporary changes in daily routines or family circumstances also disrupted parents' ability and/or motivation to maintain good practice sleep routines. Parents found maintaining sleep routines during school holidays, and even weekends, were particularly difficult especially when they were away from their usual surroundings.

The home environment.

Parents judged that aspects of the home environment placed limits on progress with their child's sleep in a variety of ways. This was particularly an issue where the child shared a bedroom with siblings. Here, where the child was prone to night wakings and they had been advised not to intervene, parents said they sometimes felt unable to comply, as they had to take account of the sibling's need for undisturbed sleep.

Parents' Views on Intervention Intensity and Mode of Delivery

Finally, this study also afforded the opportunity to explore and compare parents' experiences of SMI in terms of intervention intensity and mode of delivery.

High intensity, individually-delivered SMIs (Interventions A and B).

A consistent theme in the accounts of parents receiving a high intensity intervention was the value of its individualised nature in terms of the assessment process, formulation of a specific sleep strategy, and support during implementation of that strategy. Parents believed the detailed assessment of the child's sleep difficulties carried out in the home meant the practitioner not only fully understood the sleep difficulties, but was also able to identify

features of the home environment which may be contributing to them and/or may support or impede implementing sleep management strategies.

All parents believed the support they had received from the sleep practitioner as they implemented new sleep management strategies was critical. Many described the temptation to abandon the new strategies in moments of tiredness or multiple demands on their attention and energy. Scheduled contacts with their sleep practitioner were a source of encouragement, advice and, to some degree, accountability.

It's great.... 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. [75 (Mother), A]

She was supportive, said we were making progress, kept me going when I felt it had been a flop after all the hard work. [76 (Mother) A]

During implementation of the sleep management strategy, contacts with the sleep practitioner were via home visits or telephone calls. Parents were content with either mode of contact. However, telephone calls were regarded as less intrusive and time-consuming. Finally, parents valued the flexibility of the SMI they had received. This included both appointment times which fitted, where possible, with the family's schedules and, more substantially, the frequency and duration of support available as they implemented new sleep management strategies.

A four session, group-delivered intervention (Intervention C).

Intervention C was delivered over 4 sessions, spanning a five week period. In between each session, parents carried out specific tasks or activities to support assimilation of their learning and/or practice specific sleep management activities. The subsequent session began with a review of learning from this 'homework'. Parents reported valuing the encouragement and

advice both of the sleep practitioner and other parents. As with individually delivered interventions, parents spoke about a sense of accountability, primarily in this case to the other parents, which had helped them sustain their efforts in managing their child's sleep.

Parents identified a number of advantages to this particular mode of delivery. First, the opportunity to be with other parents was highly valued. Parents said they had gained reassurance from realising that they were not the only family with a sleep problem and that this had helped them feel less isolated. They also reported that sharing experiences made them feel more confident about tackling their own child's sleep problem. Second, parents valued the way the group format enabled them to access a range of ideas for tackling sleep problems from other parents.

...to bounce ideas off... discuss whether something is suited to your child and then go away and try something new. [94 (Mother) C]

A single half-day workshop (Intervention D).

Although the workshop was both a one-off event and less interactive, parents receiving this SMI reported similar experiences, and noted similar advantages, to those who had attended the four session group delivered intervention (Intervention C).

What really helped was other parents sharing their ideas of what had worked or what hadn't worked. It's so empowering...being in a group of people where they've got similar experiences and you take that kind of take that on.. [96 (Mother) D]

However, these parents more frequently drew attention to the sleep practitioner's expertise and knowledge compared to those who received Intervention C. This difference seems to be grounded in the fact that the mode of delivery mode was much more didactic.

Satisfaction with the mode of intervention delivery received was most variable among parents who had received Intervention D (for the other SMIs, parents consistently and strongly favoured the type of SMI they had received.) Parents receiving Intervention D whose perceived needs were most closely consistent with the expressed aims of workshop (ie. a basic grounding in the principles of behavioural management of sleep disturbance) expressed satisfaction. Furthermore, for some, the workshop format was seen as having a definite advantage over an individually delivered SMI in that it made minimal demands on parents in terms of active engagement:

I think if it had been one-to-one I'd have been feeling it was just me and feeling guilty. [97 (Mother) D]

Parents, however, who attended the workshop hoping to identify specific solutions for their child's sleep difficulty expressed frustration that the workshop content and mode of delivery meant there was no scope to respond to attendees' particular needs or concerns. A further limitation noted by some was, though developed specifically for parents of children with ND, the content of the workshop was relatively generic. This meant condition-specific issues related to children's sleep and sleep management were not addressed: this limitation was particularly referred to by parents of children with autism.

Discussion

This paper reports the experiences of parents' of children with neurodisabilities (ND) as they received, or attended, a sleep management intervention (SMI). Parents' perceptions of the role played by the SMI in achieving positive sleep outcomes was very clear and many gave quite detailed accounts of the way the various elements of the SMI had supported these achievements. In addition to positive sleep outcomes, improved parental well-being and

confidence also featured highly in parents' accounts. For some this 'off-set' a lack of substantive improvements in their child's sleep.

We did not discern large differences between SMIs in terms of parents' views of the acceptability and effectiveness of the interventions they had received. However, across the sample, parents of children with autism did emerge as being least satisfied. The key reason for this was SMIs were sometimes discerned as being inadequate in addressing, or acknowledging, the way autism may impact on sleep and the choice and implementation of sleep management strategies. These findings suggest the following may be worthwhile: reviewing the content of SMIs where the target population includes parents of children with autism; ensuring sleep practitioners are sufficiently expert in autism; and, for group-delivered interventions, consider running specific groups for a parents of autistic children.

Parents who were supported as they implemented new sleep management strategies identified this as critical to achieving positive outcomes. Interestingly, however, parents who had attended the half-day workshop (Intervention D) did not report a lack of on-going support as a barrier to achieving changes in their child's sleep. It may be particular individual characteristics affect whether or not a parent is able and motivated to sign up for, and attend, a workshop by themselves and that this is wider indicator of the personal resources they will bring to a SMI. This may have implications in terms of the decisions practitioners make about the mode of SMI offered to a parent.

A dominant theme in parents' accounts was that they came to the SMI feeling de-skilled in managing their child's sleep. They ascribed this to the presence of the neurodisability and/or associated health conditions. As reported, parents believed addressing that lack of confidence

was key to subsequent progress. It is important to note that among parents of typically developing infants, the experience of regained confidence was also observed (Tse and Hall, 2007). Further, when used as outcome measure in SMI evaluations, positive changes in parents' sense of competence are reported (Stuttard et al., 2015a). Whilst further research is required to understand whether parents of children with a neurodevelopmental disability are 'doubly jeopardised' in terms of their confidence as parents, what these findings do imply is that SMIs should nurture parents' confidence, and this should be an early and on-going element of the intervention.

The consistent and very high value placed on peer support (ie parent – parent support) certainly suggests that group-delivered interventions should be considered. However, as reported, not all parents enjoy being part of a group, and it may be a barrier to uptake. Equally, group-delivered interventions cannot offer the same intensity and individualised support that some parents and/or some sleep difficulties may need. Certainly, those parents receiving an individually delivered SMI highly valued its individualised nature and the flexible and responsive nature of support available to them as they implemented new sleep management strategies. Robust studies comparing mode of delivering SMI in terms of intervention effectiveness, and which also identify the parent and child factors which moderate or mediate effectiveness, would be extremely valuable to clinicians and other practitioners seeking to deliver SMIs.

Issues with poor compliance with SMI and intervention drop out are reported by studies conducted in the 1980's and 1990's and, to some extent, these reveal issues with the feasibility or acceptability of SMIs at that time (Mindell, 1999). Our findings reveal that, despite developments in the content and delivery of SMIs, barriers to compliance and

sustained engagement with an SMI remain and are wide-ranging. Many were consistent with those identified by Tse and Hall, 2007 and also align with professionals' views (eg. Stuttard et al., 2015b). Implementing changes in bedtime routines, or how night wakings are managed, can be very demanding on parents' emotional and physical resources. Progress can also be stymied by unanticipated or uncontrollable events or circumstances and/or unsupportive, or resistant, partners or grandparents. It was also apparent from some parents' accounts that a lack of options regarding sleeping arrangements (e.g. child having to share bedroom with a sibling) was a significant barrier to achieving any progress with their child's sleep. These findings highlight the importance of assessing the wider context in which the parent will be implementing an SMI. Preliminary work with other family members and/or attending to housing needs may be appropriate and necessary first steps. Our findings also suggest that it is important to assess whether parent's capacity to engage with an SMI is (even temporarily) compromised. Finally, it reiterates the importance of a 'menu' of SMIs being available in order that, after careful assessment, practitioners can choose the one most appropriate both to the parent and the child (Stuttard et al., 2015a).

The study reported in this paper makes a contribution to a very limited evidence base on parents' experiences of receiving a sleep management intervention. It concerns parents of children with neurodevelopmental disabilities – a population where a higher incidence of sleep disturbance is reported. In addition, it compared experiences different types of SMIs, both in terms of their intensity and mode of delivery. Care was taken to represent in the sample recruited to the study a range of factors which may impact on parents' views and experiences including, intervention outcomes, socio-demographic factors and family circumstance. Target samples were achieved though we would note that it was not possible to categorise all participants in terms of their intervention outcomes. A key limitation to the

study is that parents' views and experiences were only collected at one time point, around 18 weeks after completing a SMI. Whilst this allowed us to explore issues associated with maintenance of outcomes, a longitudinal study design (commencing prior to, or during, the SMI) would offer further insights and allow us to more fully understand this topic. Given the exploratory nature of the study (which is important and appropriate given the lack of previous research) a wide range of topics were covered in the interviews. Future research may benefit from focusing on specific issues. Finally, it would be interesting and useful to replicate the study in settings where a number of SMI's are available and parents are triaged according to level of need and/or severity of the sleep problem.

To conclude, the findings from this study provide useful evidence for practitioners seeking to introduce or develop the provision sleep management interventions for parents of children with neurodevelopmental disabilities. It has highlighted that psycho-educational approaches to changing sleep management practices is not simply a case of educating parents. Rather a number of other issues need to be considered, including, for example, addressing parenting confidence, ensuring parents are adequately supported as they seek to change their child's sleep, encouraging consistency across caregivers, and the adequacy of housing or living arrangements. It has also explored the perceived benefits and disadvantages of different modes of delivery and intensity. Finally, the findings raise questions about the suitability of 'generic' sleep management interventions for at least some parents of children with neurodevelopmental disabilities.

Endnotes

1 Morris et al. (2013) offer a consensus definition of neurodisability as: "congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a

broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion and behaviour” (p3)

2 Each direct quote is referenced as follows: [participant identification number (mother vs father) intervention identification letter].

References

- Allard, A., Fellowes, A., Shilling, V., Janssens, A., Beresford, B. & Morris, C. (2014) Key health outcomes for children and young people with neurodisability: qualitative research with young people and parents. *BMJ Open*, 4, 4.
- Bruni, O. & Novelli, L. (2010) Sleep Disorders in Children. *Clinical Evidence*, 9, 2304.
- Dorris, L., Scott, N., Zuberi S., Gibson, N. & Espie C. (2008) Sleep problems in children with neurological disorders. *Developmental Neurorehabilitation*, 11, 95-114.
- Galland, B. & Mitchell, E. (2010) Helping Children Sleep. *Archives of Diseases in Childhood*, 95, 850-3. doi: 10.1136/adc.2009.162974
- McConkey, R., Kelly, F. & Craig, S. (2011) Access to respite breaks for families who have a relative with intellectual disabilities. *Journal of Advanced Nursing*, 67, 1349-1357.
- Mindell, J. (1999) Empirically supported treatments in pediatric psychology: bedtime refusal and nightwakings in young children. *Journal of Pediatric Psychology*, 24, 465-481
- Ritchie, J., Spencer, L. & O'Connor, W. (2003) Carrying out qualitative analysis. In Ritchie J, Lewis J (eds) *Qualitative Research Practice*. London: Sage.
- Miles, M. B. & Huberman, M. (1994) *Qualitative Data Analysis: A Sourcebook of New Methods*. 2nd Edition. Beverly Hills, CA: Sage Publications.
- Morris, C., Janssens, A., Tomlinson, R., Williams, J. & Logan, S. (2013) Towards a definition of neurodisability: a Delphi survey. *Developmental Medicine and Child Neurology*. 2013. DOI: 10.1111/dmcn.12218.

- Newman, C., O'Regan, M. & Hensey, O. (2006) Sleep disorders in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 48, 564-568
- Nikolopoulou, M. & St James-Roberts, I (2003). Preventing sleeping problems in infants who are at risk of developing them. *Archives of Disease in Childhood*, 88, 108-111.
- Quach, J., Gold, L., Hiscock, H., Menash, F., Lucas, N., Nicholson, J. & Wake, M. (2013) Primary healthcare costs associated with sleep problems up to age 7 years: Australian population-based study. *BMJ Open*, 3:e002419 doi:10.1136/bmjopen-2012-002419.
- Stores G. (1999) Children's sleep disorders: modern approaches, developmental effects, and children at special risk. *Developmental Medicine & Child Neurology*, 41, 568–573
- Stores, G. & Stores, R. (2012) Sleep disorders and their clinical significance in children with Down syndrome. *Developmental Medicine and Child Neurology* DOI: 10.1111/j.1469-8749.2012.04422.x
- Stuttard, L., Beresford, B., Clarke, S., Beecham, J. and Curtis, J. (2015a) A preliminary investigation into the effectiveness of a group delivered sleep management intervention for parents of children with intellectual disabilities, *Journal of Intellectual Disabilities*, 19, 342-55
- Stuttard, L., Clarke, S., Thomas, M. and Beresford, B. (2015b) 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). DOI:10.1111/cch.12250
- Tietze A, Blankenburg M, Hechler T, Michel E, Koh M, Schluter B, Zernikow B. Sleep disturbances in children with multiple disabilities. *Sleep Medicines Review*, 16, 117-127 doi:10.1016/j.smr.2011.03.006.
- Tse, L. & Hall, W. (2007) A qualitative study of parents' perceptions of a behavioural sleep intervention. *Child: care, health and development*, 34, 162-172.

Wiggs L. (2009) Behavioural aspects of children's sleep. *Archives of Diseases in Childhood*, 94, 59-62. doi:10.1136/adc.2007.125278

DO NOT COPY

Table 1: Mode of participation in research by sleep management intervention

	Interview	Focus group	<i>Total</i>
Intervention A	8	-	8
Intervention B	4	-	4
Intervention C	8	7	15
Intervention D	8	-	8
<i>Total</i>	28	7	35

Table 2: Progress¹ towards achieving specific sleep goal at 12 weeks post intervention

	Improved	Little change	Deteriorated	Missing	<i>Total</i>
Intervention A	6	1	0	1	8
Intervention B	0	2	0	2	4
Intervention C	8	3	0	4	15
Intervention D	3	4	0	1	8
<i>Total</i>	17	10	0	8	35

¹Progress was tracked using a 10 point rating scale completed pre- and post intervention, and then as 12 and/or 24 weeks follow-up. At each time point, parents used the rating scale to indicate perceived progress towards the goal for their child's sleep set at the start of the intervention.

Table 3: Parents' socio-demographic characteristics and nature of child's neurodisability

		N
Parenting status	Mothers	30
	Fathers	5
Language	English as first language	34
	English not first language	1
Paid work outside home	Yes	12
	No	23
Mothers received intervention with/ without partner	With partner	9
	Without partner	26
Parents' highest educational qualification	No further/higher education	13
	Attended further/higher education	22
Nature of child's neurodisability: (parent-report)	Autism only	11
	Autism & other neurodisability	10
	Neurodisability only	14

Figure 1: Overview of interventions

	Mode of delivery	Age range	Overview of the intervention	Duration
High intensity				
A	One-to-one	0-5 yrs	Individualised assessment leading to sleep strategy which is implemented by parents. Parents are supported during the implementation phase via at least weekly home visits and/or telephone calls.	6-8 weeks
B	One-to-one	0-5 yrs	Individualised assessment leading to a 'sleep plan' which is implemented by parents. Parents are supported during the implementation phase through fortnightly home visits and/or attendance at Sleep Clinic sessions at local children's centre.	12-16 weeks
Medium intensity				
C	Group	3-18 yrs	Comprises four 3 hour sessions. A manual sets out session structures, contains handouts and other teaching materials. Didactic teaching, group discussion and learning activities are used. Parents and caregivers are asked to complete homework between sessions such as completing sleep diaries and environmental assessments as well as plan and implement bedtime routines. All homework is discussed at the next session.	Delivered over 5 week period
Low intensity				
D	Workshop	2-19 yrs	Five hour workshop covering children's sleep, good sleep management practice and basic strategies to support parents in establishing new routines. A manual sets out the structure and content of the workshop and contains handouts and other teaching materials. Predominantly didactic teaching with some group discussion/group-based learning activities.	Single session