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In this article...

- Reviewing the evidence for sleep hygiene education in children with developmental disabilities
- Use of participatory research in developing a sleep hygiene education tool
- Factors that can help or hinder the success of this sleep intervention

A sleep hygiene tool for children with developmental disabilities

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Key points

Sleep hygiene education is used to manage sleep problems in children with developmental disabilities, but the evidence base is limited

Experience-based co-design is a participatory research method that promotes professional and public involvement in service improvement

A systemically developed sleep hygiene education tool for children with developmental disabilities has 43 advice points for practitioners to choose from

An underpinning programme theory explains how sleep hygiene education should improve children's sleep

Greater awareness is needed of sleep problems in children with developmental disabilities and the support available

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Abstract This article describes a co-design study to develop a sleep hygiene education tool for children with developmental disabilities and behavioural sleep problems. The tool is underpinned by a programme theory, which explains how sleep hygiene education should work to improve children's sleep. In three co-design workshops, eight parents and six practitioners debated a preliminary sleep hygiene education tool, using themes developed from an earlier evidence review and exploratory study into parent and practitioner experiences of sleep hygiene education. This participatory research established stakeholder acceptability of the SHE tool and confirmed the often-hidden contextual factors that can help or hinder its success, informing the underpinning programme theory.

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Severe and chronic sleep problems, such as difficulties falling asleep and multiple night awakenings, are common in children with developmental disabilities (Bonuck and Grant, 2012). These are linked to negative outcomes for the child, and include impaired concentration and mood and behavioural difficulties (Mazurek and Petroski, 2015; Beresford et al, 2012). Family members may experience increased stress, as well as relationship and employment difficulties, from managing children's sleep difficulties on a long-term basis (Bourke-Taylor et al, 2013; Roberts et al, 2019).

Health and social care practitioners are advised to first identify and address physical causes of sleep problems, such as epilepsy or breathing difficulties, and assess for behavioural causes linked to parental management style, such as inconsistent boundaries (Malow et al, 2014). Usual first-line treatment for sleep problems with behavioural origins is sleep hygiene education (SHE) (Blackmer et al, 2016), which advises parents on creating positive sleep environments and routines that promote optimal sleep.

An unpublished scoping review of SHE for sleep problems in children with developmental disabilities identified six different categories of SHE advice components, for which the evidence was mixed:

- Sleep timing;
- Bedtime routines;
- Behaviour management;
- Environment;
- Physiological factors;
- Communication adaptations (Sutton, 2017).

It also found limited evidence to support SHE as a credible, primary sleep intervention. Only two intervention studies explored SHE as a standalone treatment: Adkins et al (2012) found it improved sleep

efficiency in children with autism, whereas Piazza et al (1997) concluded it was less effective than a comparative behavioural intervention, although the study lacked methodological rigour.

One qualitative study – by Beresford et al (2012) – explored professional and parent views of SHE combined with other behavioural interventions. This identified enablers (such as practitioners' specialist sleep knowledge) and barriers (such as parents' lack of readiness to engage), but had limited value in considering SHE as a distinct intervention. The scoping review found no evidence as to how policy or organisational factors could affect intervention success, and results overall highlighted a need for further research into SHE and its application for sleep problems in children with developmental disability.

Delivering SHE to families is complex and requires consideration of a range of factors, such as:

- Social context;
- Parent/practitioner relationships and levels of support;
- How these can impact on the success or failure of SHE in improving children's sleep.

It is essential to identify these often hidden elements so practitioners can understand how complex interventions like SHE create change, and ensure only best practice is repeated (Funnell and Rogers, 2011). Developing a programme theory that underpins the intervention can help with this by explaining the process of change in a detailed way (Chen, 2015). Increased pressure on health and social care resources makes it even more important that practitioners explicitly understand the SHE advice they give and only deliver care that is relevant to individual need (Bradley et al, 2014).

Stakeholder research

The Medical Research Council (2008; 2000) offers a helpful framework for developing complex interventions and the underpinning evidence. The process begins with an evidence review, which is used to inform additional exploratory stakeholder research and build intervention understanding. The evidence review described above was used to inform a qualitative study of the SHE experiences of nine parents of children with developmental disability and 11 practitioners from health and social care (Sutton et al, 2019a). The review and study findings were synthesised and organised into six themes, summarising the evidence base, stakeholder views on

Box 1. **Sleep hygiene education tool – advice for practitioners**

Practitioners can select appropriate advice from the following categories.

1. Sleep timing
- 1.1 Set consistent bedtimes and wake times (including holidays and weekends)
- 1.2 Set age-appropriate bedtimes
- 1.3 Encourage age-appropriate daytime napping
- 1.4 Avoid late-afternoon napping
- 1.5 Avoid excessive time in bed

2. Bedtime routines
- 2.1 Set a relaxing routine
- 2.2 Discourage television or blue-light-emitting devices at bedtime (consider blue-light blocker sunglasses if child resistant)
- 2.3 Consider alternative therapies and relaxation techniques
- 2.4 Limit bedtime rituals
- 2.5 Ensure routine activities are consistently ordered and timed
- 2.6 Ensure routine is of 20-45-minute duration

3. Behaviour management
- 3.1 Ensure bedroom is not used as a punishment setting
- 3.2 Avoid soothing to sleep with a bottle/breast when child is >6-12 months old
- 3.3 Incorporate rewards that are meaningful to the child
- 3.4 Set, and stick to, limits
- 3.5 Ensure child falls asleep and sleeps alone in their own bed
- 3.6 Put child to sleep drowsy
- 3.7 Give minimal interactions during nighttime feeds and night awakenings
- 3.8 Encourage child to think about problems/plans before going to bed

4. Environment
- 4.1 Keep quiet noise levels at sleep times
- 4.2 Maintain room temperature at 16-20°C, and select bedding and sleep clothes to maintain comfortable body
- 4.3 Ensure darkened bedroom (blackout blind)
- 4.4 Provide bedroom with familiar layout and calm decoration
- 4.5 Allow security object to promote self-soothing
- 4.6 Consider sensory sensitivities of the child
- 4.7 Ensure bed is comfortable (consider sleep systems)
- 4.8 Remove or hide stimulating toys that are in the bedroom
- 4.9 Use nightlight, or red modelling bulb if preferred

5. Physiological
- 5.1 Maintain healthy diet, including limiting fat and sugar intake
- 5.2 Encourage daily exercise (but avoid in the late evening)
- 5.3 Ensure child is exposed to plenty of light in the day
- 5.4 Avoid smoking and alcohol
- 5.5 Light meals only near bedtime
- 5.6 Limit caffeine intake
- 5.7 Ensure child uses toilet before bed
- 5.8 Encourage milk and give foods that are rich in tryptophan/melatonin with complex carbohydrates at suppertime
- 5.9 Ensure child's individual hydration needs are met
- 5.10 Avoid blackcurrant juice in the evenings

6. Communication adaptations
- 6.1 Give clear expectations, prompts and cues
- 6.2 Incorporate augmentative communication strategies
- 6.3 Encourage regular timing of all meals
- 6.4 Consider visually modelling the routine using a doll
- 6.5 Ensure bedroom is only used for sleep and for calm activities

"Review results highlighted a need for further research into sleep hygiene education and its application for sleep problems in children with developmental disability"

SHE and how SHE should be implemented. This informed a co-design study to:

- Systematically develop and confirm a SHE tool for children with developmental disability;
- Develop a programme theory underpinning SHE and offering an explicit understanding of what SHE does, how it is delivered and how it is supposed to work to improve sleep (Sutton et al, 2019b).

Co-design study

The study used experience-based co-design (Bit.ly/PoCEBCDToolkit), a participatory research method that promotes professional and public involvement in service improvement (Creswell, 2007). Using this method, parents and practitioners were invited to debate a preliminary SHE tool using themes developed from the earlier evidence review and exploratory study into parent and practitioner experiences of SHE.

The six themes were illustrated in an auditory podcast drawn from the exploratory study parent interviews reported by Sutton et al (2019a). This podcast was used to trigger debate in three co-design workshops, involving eight parents of children with developmental disability and sleep problems, along with six practitioners with experience of SHE from social care and voluntary organisations. Parent and practitioner 'co-designers' were invited to:

- Establish how parents and practitioners could work together to ensure SHE was effective;
- Describe an exemplar parent journey in securing professional SHE;
- Develop understanding of what makes SHE work;
- Confirm the acceptability of the developing SHE tool.

Insights and ideas were captured on a wall-sized visual, using the person-centred planning tool, Planning Alternative Tomorrows with Hope (PATH), which helped consolidate findings and focus discussion (Sanderson and Lewis, 2012). The workshops were recorded on audio and video, before being transcribed; the data was then thematically analysed in relation to the discussion themes, as outlined by Braun and Clarke (2006). Findings from the evidence review, and exploratory and co-design studies were synthesised to iteratively construct a SHE tool and underpinning programme theory for children with developmental disability.

The SHE tool

The SHE tool has six categories and 43 advice components for practitioners to select from (Box 1). To ensure the tool's validity, each advice point was evidenced by at least two review citations, or one citation plus further research evidence or co-designer agreement.

Programme theory

The supporting programme theory advises practitioners on using the tool correctly. The six discussion themes were:

- Reframed as SHE intervention desired outcomes (Box 2);
- Listed in a matrix with the activities, processes, resources, and programme and non-programme factors (hidden contextual factors) contributing to the achievement or non-achievement of each desired outcome.

Desired outcome 1: parents and practitioners have a shared understanding of what constitutes a sleep problem

Before SHE is implemented, parents and practitioners need to develop a common appreciation of what constitutes a sleep problem in a child with developmental disability. Measures that can help include:

- Training generic and sleep practitioners in sleep problem recognition;
- Encouraging practitioners to adopt a positive attitude toward sleep;
- Raising parents' expectations that children's sleep can improve.

Contextual factors that prevent parents from recognising children's sleep problems include coping strategies (such as co-sleeping), which can mask the problem, or relatives insisting parents take a stoic attitude towards managing their child's sleep.

The SHE intervention aims to make screening for sleep problems standard practice for all children, not just those with developmental disability; parent co-designers believed this would help 'normalise' enquiries about sleep, so parents were more willing to admit their child had a sleep problem. Parents also:

- Wanted to be empowered to screen their children themselves ;
- Asked to see screening tools embedded in their personal child health record.

Finally, the intervention aims to encourage more parents to seek help early, through media campaigns that increase awareness of children's sleep problems – which leads to the next outcome.

Desired outcome 2: sleep services are well publicised and accessible for parents

Services can be made more accessible by:

- Accepting direct referrals from parents;
- Having broad referral criteria that include all children, regardless of age or type of developmental disability;
- Having short waiting lists;
- Having good geographical coverage.

Parent co-designers thought parents should be able to access mainstream sleep services first, before being signposted to specialist sleep services; they explained that this would help 'normalise' sleep problems and encourage more parents to access the sleep help they need.

Publicising specialist sleep services widely would help raise awareness among parents and generic practitioners. However, the contextual issue of some parents having low literacy levels or limited internet access was a potential barrier to accessing available support. This leads to the next two intermediate outcomes, which can be addressed concurrently.

Desired outcome 3: parents and practitioners develop safe and supportive relationships

For patients to follow SHE advice, patients and practitioners need to build a trusting working relationship. The intervention

Box 2. **Sleep hygiene education tool: desired outcomes**

- Parents and practitioners have a shared understanding of what constitutes a sleep problem
- Sleep services are well publicised and accessible for parents
- Parents and sleep practitioners develop a safe and supportive relationship
- Parents and sleep practitioners improve their understanding of the sleep problem
- Regularity and quality of child's sleep improves
- Quality of life improves for the family

helps to achieve this by training practitioners on good interpersonal skills to use in their work with patients.

Parent co-designers stressed how important it was for practitioners to:

- Appreciate their situation;
- Communicate sensitively;
- Offer reassurance, so they can have confidence in the advice they receive.

However, some parents may mistrust practitioners because of poor experiences in the past, and this can be a barrier to success. Another influencer was the amount and type of support offered to parents throughout their contact with sleep services. As an example, parents wanted the option of home visits, as home was where they felt most comfortable discussing the sensitive topic of sleep.

It was agreed that the support provided should be driven by what parents need. Developing a supportive partnership takes time, but can be built while assessing the sleep problem, as in the following outcome.

Desired outcome 4: parents and practitioners improve their knowledge of the sleep problem

Increasing parents' and practitioners' knowledge of the nature and causes of the sleep problem is a focus of SHE. The intervention works to provide a comprehensive sleep assessment through adequate resourcing of practitioners' time, allowing practitioners to observe the child at home at bedtime over multiple sessions, while liaising with the multidisciplinary team and partner organisations. Co-designers said this would help parents feel that practitioners had taken the time to get to know their child and were basing their advice on the information collected. Factors influencing success included whether parents gave assessment information honestly and how effectively practitioners worked with partner organisations.

The intervention also works to provide a competent sleep assessment. This starts with screening the child for physical and psychological co-morbidities that could be a cause of the sleep problem, which, if overlooked, can affect the success of the SHE intervention. Practitioners are trained to use sleep histories, sleep diaries and validated outcome measures to:

- Uncover multiple causal factors of the sleep problem;
- Understand the nature of the problem;
- Establish a baseline recording of it.

They also need to be skilled in interpreting sleep assessment findings, working in partnership with parents, and using a psychological formulation to summarise the child's strengths and behavioural causes of sleep problems. This may include identifying sleep disorders, such narcolepsy or circadian rhythm sleep–wake disorders, which require alternative interventions to SHE.

A non-programme or contextual factor that could hinder success – and may be largely outside the practitioner's control – is commitment from parents. Co-designers also highlighted the need for a supportive sleep assessment process, which might include alternative methods of recording sleep information using visual prompts, easy-read sleep diaries or smartphone apps.

Achieving a detailed knowledge of the sleep problem is a crucial step towards tailoring SHE advice and identifying the support needs of the family; it feeds into the final outcomes below.

"Parents wanted to be empowered to screen their children themselves and asked to see screening tools embedded in their personal child health record"

Desired outcome 5: regularity and quality of the child's sleep improves

This direct focus of the SHE effort describes how the child's sleep can be improved. The SHE tool includes 43 advice components and it is not realistic or appropriate to ask parents to achieve all of these. The intervention works to deliver effective SHE by training practitioners to customise sleep advice selected from the SHE tool according to their assessment findings and the needs of the family. This may include appropriate referrals to other generic practitioners or support organisations based on assessed needs.

Co-designers stressed the importance of backing up SHE advice with an explanation of the rationale behind it and psychoeducation to help motivate parents to follow it. Many contextual factors could affect success, including parents' mental health or competing health issues in the child. This makes explicit the complexity of SHE.

Change to practitioners' time is resourced to ensure the levels of support needed for parents to continue with SHE advice is achieved. To address any perceived power imbalances, practitioners should actively invite parents to bring peer supporters to every meeting. Co-designers also recommended having paid 'parent buddies' in the sleep teams who could coach parents on following the advice.

Contextual factors at the programme's boundaries include partner organisations, such as schools, not following sleep advice and allowing children to sleep in the day. This can jeopardise progress made by parents and demonstrates the complexity of the support needed.

Desired outcome 6: quality of life improves for the child and family

The success of the SHE intervention is monitored through quality-of-life outcome measures at both the start and the end of the intervention. Alternatively, patients may be asked to complete a qualitative evaluation questionnaire to show how quality of life has improved by way of follow-up. Administering this survey, and ensuring completion of the documentation involves extra time and commitment from practitioners, which needs to be resourced. Success also depends on the contextual factor of parents having the time and motivation to fill out the documentation. The intervention supports parents to maintain sleep progress by offering follow-up support; co-designers highlighted the importance of continuing practitioner support for those parents who need it.

Parent support groups, backed by practitioners, are another powerful tool in helping parents continue with SHE advice, rather than reverting back to coping strategies they had used previously and that had been unhelpful. However, practitioners need to be resourced to support these groups and not all parents will be comfortable accessing them.

Discussion

We now have a systematically developed SHE tool for children with developmental disability, with 43 advice points for practitioners that are supported by research or stakeholder validation. The tool is underpinned by a programme theory, which increases practitioner understanding and helps to achieve effective delivery of SHE to improve children's sleep.

A strong focus of the programme theory is raising awareness of sleep problems in children with developmental disability and empowering parents to ask for professional help. This is in agreement with the Family Fund's (2013) report, *Tired all the Time*, which argued that there is a need for policy makers to reprioritise sleep

problems. The need to inform parents of the rationale underpinning SHE and for psycho-education is supported by research from Beresford et al (2016), who found enhancing parents' sleep knowledge was influential in improving children's sleep. In addition, a review of behavioural sleep interventions by Kirkpatrick et al (2019) supports the recommendation that parents should receive continuous support post intervention.

Experience-based co-design was found to be an effective participatory research method, which actively encourages professional and public involvement in the research process. The audio podcast was particularly powerful in eliciting co-designer responses and feeding back parents' views to practitioners. However, there was limited guidance on how to facilitate the co-design groups and keep co-designers focused. Locock et al (2014) noted similar limitations, and introduced tools such as Quality Circles to keep groups on track. In our study, parents at the first co-design event often digressed to broader issues around disability diagnosis or education – however, introducing the PATH tool in subsequent events successfully focused discussion on the main purpose and aims of the study.

It could be argued that the co-design process may stifle authentic expression if parents feel unable to speak candidly in the presence of practitioners. This is a potential limitation of the experience-based co-design method, and Wainwright et al (2014) argued that separate stakeholder groups could be more effective in gaining genuine participation. In this study, we facilitated events in a supportive way to minimise the effects of psychosocial factors, such as obedience, dominance and conformity on group processes.

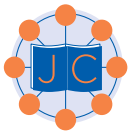
Other participatory approaches, such as the Delphi method, often involve service commissioners to ensure ideas for service improvement are based on cost/resource considerations as well as clinical expertise and service-user opinion (Snape et al, 2014). Future research that includes consulting with commissioners, and policy developers would enhance the feasibility of the SHE tool and programme theory.

"The SHE tool contributes to the evidence base that supports SHE as a credible first-line intervention for behavioural sleep problems in children with developmental disability"

The way forward

The study findings enhance our understanding of how SHE for children with developmental disability and sleep problems is supposed to work to improve sleep. The SHE tool and supporting programme theory contribute to the evidence base that supports SHE as a credible, distinct and first-line intervention for behavioural sleep problems in children with developmental disability.

The final development step in the MRC's framework is studies focusing on the modelling process and outcomes. This would involve translating the programme theory's desired outcomes into an operational manual for use with the SHE tool, and piloting it with relevant primary care teams. Once complete, this would open the way for a main evaluative study, to test the effectiveness of the developed SHE intervention. **NT**



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