

Sleep hygiene education and children with developmental disabilities: findings from a co-design study

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Sleep hygiene education and children with developmental disabilities: findings from a co-design study.

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Keywords:	children, developmental disabilities, sleep hygiene education, experience based co-design, programme theory
Abstract:	<p>This qualitative study develops a programme theory demonstrating the complexity embedded in sleep hygiene education (SHE) as an intervention to improve sleep problems in children with developmental disabilities (DD). In co-design workshops, eight parents and six sleep practitioners deliberated discussion themes developed from a thematic analysis of exploratory study data, guided by a 'trigger' podcast illuminating parents' narratives of SHE. A SHE tool underpinned by programme theory abstracted to mid-range theories of change was developed. Analytical themes were proposed: the need to enhance the legitimization of children's sleep problems and consider the nature of customisation, knowledge sharing, health expectation and impact of sleep service rationing and gaming strategies on implementation success. Policy and practice implications include a need to raise the public profile of children's sleep problems and promote parental involvement in intervention implementation. Further research is needed to test out this theory-driven framework for evaluating SHE.</p>

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Introduction

Children with developmental disabilities (DD) (Table 1) commonly experience severe and persistent sleep problems (Bonuck and Grant, 2012; Sutton, 2011; Tietze et al., 2012), which are associated with negative outcomes for the child (e.g., daytime challenging behaviour and impaired educational performance) (Beresford et al., 2012; Galland and Mitchell, 2010) and the family (e.g., increased stress and relationship difficulties) (Family Fund, 2013). To ensure appropriate treatments are advocated, current evidence suggests that sleep problems should be assessed to eliminate physiological causes, and to identify those which are behavioural in origin (linked to parental management issues) (Malow et al., 2013; McDaid and Sloper, 2009). An essential first intervention for behavioural sleep problems is sleep hygiene education (SHE) (National Institute for Health and Care Excellence, 2013; Vriend et al., 2011) which advises parents on creating optimal sleeping conditions for their child and exposes them to “*activities and cues that prepare them for and promote appropriately timed and effective sleep*” (Jan et al., 2008, p.1344) (e.g., creating consistent bedtime routines, avoiding caffeine and encouraging daytime exercise).

[Table 1 to be inserted here] Operational definition of developmental disabilities (DD).

(This has been specifically developed for the purposes of this study and encompasses a variety of neurological conditions).

Developing a theoretical understanding of SHE.

SHE can be viewed as a complex intervention which has multiple interacting components such as behaviours, organisational methods and settings. It is often difficult to identify the active ingredients which make complex interventions work, however, it is important that services engage in systematic evaluations so that intervention effectiveness can be repeated (Medical Research Council, 2000, 2008). It is common for individuals working in health or social care organisations to have a poor understanding of how interventions bring about change, and they may engage in un-informed implementation of ineffective practices for years (Funnell and Rogers, 2011). Indeed, SHE is currently supported by theories based on popular wisdom (Galland and Mitchell, 2010, Jan et al., 2008) and it is routinely implemented without explicit explanation of what SHE programme activities are supposed to achieve. Notwithstanding, in the existing cost-conscious climate of prudent healthcare (Bradley and Willson, 2014) it is essential that practitioners deliver evidence-based, transparent care which is relevant to individual need.

The Medical Research Council (MRC) framework for evaluating complex interventions (2000, 2008) advises that intervention evaluations should be underpinned by an evidence review that is also augmented by additional primary research with stakeholders to build theoretical understanding. Accordingly, an earlier scoping review (Author 1 []) identified mixed evidence underpinning SHE content and a limited theoretical base. Review findings informed the development of a preliminary, evidence based SHE tool for children with DD and design of a subsequent exploratory investigation into the experiences of parents and sleep practitioners (from health and social care organisations) regarding SHE. A thematic analysis (Braun and Clarke, 2006) of exploratory study data identified parent and sleep practitioner themes which were synthesised with review findings and summarised as six overarching themes. These

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2
3 represented pre-implementation challenges and achievement of intermediate and ultimate
4
5 outcomes culminating in improved sleep and quality of life (Table 2).
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11 The current, co-design study aimed to build on collated evidence, co-create and develop the
12 preliminary SHE tool and further build a theoretical understanding of SHE by constructing a
13 programme theory (Astbury and Leeuw, 2010; Chen, 2015). Programme theory comprises a
14
15 'theory of change' which describes the core processes by which change occurs and a 'theory of
16
17 action' which explores what an intervention does to activate the outcomes espoused in a theory
18
19 of change (Funnell and Rogers, 2011). Programme theory development provides a fresh
20
21 consideration of the familiar intervention of SHE and helps to clarify a distinction between
22
23 implementation failure (the intervention is performed incorrectly), or theory failure (intervention
24
25 performed correctly, but was still unsuccessful) (Funnell and Rogers, 2011) to ensure SHE can
26
27 be replicated effectively and evaluated reliably in a theory driven manner.
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33 Co-design study findings advance the knowledge base supporting SHE in the following ways:
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- 36 1. Presents an evidenced based SHE tool for children with DD.
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- 40 2. Develops a systematic understanding about what SHE does, how it is delivered and
41
42 how it is supposed to work to improve sleep (programme theory).
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- 46 3. Links programme theory with mid-range theories of change which increases
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48 transferability.
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- 51 4. Develops explanatory analytical themes which demonstrate SHE complexity.
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3 **[Table 2 to be inserted here] Six co-design study discussion themes.**
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11 **Method.**

12 **Research design and overview of the study.**

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18 A participatory methodology approach was adopted. This champions collaborative research
19 'with' participants who are viewed as equal research partners, rather than as subjects who are
20 being researched and incorporates an action agenda (Creswell, 2007; Reason and Bradbury,
21 2001). The Experience Based Co-Design (EBCD) (The King's Fund, 2014) participatory method
22 was drawn upon. This is primarily a public and professional involvement, service improvement
23 tool that recommends a series of activities to plan for change with stakeholders (Figure 1). The
24 standard EBCD design can be adapted to suit different settings and budgets (Donetto et al.,
25 2014; Locock et al., 2014), and in the present study, it was modified as follows (Figure 2):
26
27 Stages 1 and 2 were addressed by the Community Learning Disability Nursing experience of
28 [Author 1] and the findings of the earlier scoping review and exploratory study which produced
29 six overarching discussion themes (Table 2) to flexibly guide co-design group debate. The next
30 step of producing a service user film underwent a novel adaptation: a 'trigger' podcast was
31 developed from the audio recorded exploratory parent interviews using an Audacity software
32 package. The member checked, preliminary parent themes from the exploratory study, were
33 portrayed by selecting exemplar parent voice extracts and the final podcast was reviewed by the
34 research team for accurate representation. Instead of using visual imagery, it was felt that the
35 audio channel of communication could rouse the creation of mental images in listener's minds
36 (Rodero, 2012), stimulating a personal connection with emotional touchpoints and rich
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3 discussion. Stage 4 was omitted as the earlier exploratory study involved a second practitioner
4 focus group, in which practitioners gave their approval to share validated themes with parents.
5
6 The next three EBCD steps were condensed into a parent only, and two joint parent and sleep
7 practitioner workshops in which the podcast was broadcast and co-designers co-created a SHE
8 tool and iteratively developed a programme theory. Finally, the celebration event was replaced
9
10 with the dissemination of research findings to stakeholders through the conduit of a lay
11 summary.
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21 **[Figure 1 to be inserted here] Experience based co-design (King's Fund, 2014).**
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27 **[Figure 2 to be inserted here] Overview of adapted co-design method.**
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32 **Ethics**

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35 Institutional [IDENTIFIER TO BE INSERTED FOLLOWING REVIEW] ethical approval was
36 obtained. The study as framed as a service evaluation from the perspective of NHS ethical
37 reviewers. It was not carried out on NHS premises and did not recruit parents or practitioners
38 through the NHS. Accordingly, confirmation was received from the Health Research Authority
39 the 10th April 2015 that Research Ethics Committee (REC) approval was not required. All
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41 participants gave informed written consent to participate in the co-design events.
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50 **Participants.**

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53 A purposive sample of 21 parents and eight sleep practitioners were recruited from social care
54 teams and UK voluntary organisations supporting families of children with DD. Parents were
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invited to participate if (i) they had a child with DD aged 3-18 years with experience of sleep problems, and (ii) had some experience of SHE to treat their child's sleep problems.

Practitioners were invited to take part if (i) they had at least six months experience of supporting families of children with DD aged 3-18 years with sleep problems, and (ii) were experienced in the use of SHE. Each event ran for two hours and was held at parent-friendly voluntary organisation meeting rooms. Participant, event facilitator and venue availability were collected to set dates and times for the three co-design events. A total of eight parents and six sleep practitioners took part (Table 3 & 4).

[Table 3 to be inserted here] Parent participant characteristics..

[Table 4 to be inserted here] Sleep practitioner participant characteristics.

Procedure

Co-designers were presented at the start of each event with five specific aims: 1) To gather views on how sleep practitioners and parents should work together to ensure families of children with DD receive effective sleep advice[1]# and support with sleep problems. 2) To focus on what a parent's journey toward receiving professionally supported sleep advice should look like. 3) To really understand what makes effective sleep advice and support work. 4) To think systematically about what sleep practitioners need to do when they advise and support families with sleep problems. 5) To explore parent/sleep practitioners' views on the acceptability of sleep advice content. In the first co-design event, parents were shown the six discussion themes (Table 2) and emerging ideas around process and contextual factors from the exploratory study identified by the research team, and invited to confirm, challenge or add to them. As part of the iterative process, they were asked to discuss what actions needed to happen on a parent, professional, organisational and policy level to improve how families were supported with sleep.

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3 Parents were then invited to listen to the podcast, reflect on and share any new insights which
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5 its broadcast may have triggered.
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11 To draw together emerging ideas from parent co-designers and enable effective facilitation at
12 the second event (parent and practitioner) a wall sized representation of the six discussion
13 themes and emerging constructions was prepared, based on an adapted version of the person
14 centred planning tool: the Planning Alternative Futures with Hope 'PATH' (Pearpoint, O'Brien
15 and Forest, 1998). This is a planning style used with individuals which helps them understand
16 complex situations and take control over change (Sanderson and Lewis, 2012). It was felt this
17 mirrored a participatory approach and served as a constant visual reminder of workshop aims to
18 keep data collection focused. Co-designers were firstly asked to consider the ultimate goal of
19 SHE 'Quality of life improves for the family' and asked to record on post-it notes how success
20 would make them feel which were placed on the PATH model. The PATH planning approach
21 then brings participants back to the present and requires them to examine what life is like now.
22 As indicated by Sanderson and Lewis (2012), this creates a tension between the existing
23 problem and ultimate goals, and motivates the group to plan for change. Accordingly, co-
24 designers were asked to consider discussion theme 1 'Parents and practitioners have a shared
25 understanding of what a sleep problem is' which reflected the start of a family's journey towards
26 improved sleep. Co-designers' constructions or priorities for sleep service improvement were
27 recorded on the wall sized PATH model under theme 1's column and subsequent discussion
28 themes were deliberated in turn and responses recorded. The podcast was also played to the
29 group and their reactions recorded under the appropriate discussion theme columns.
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3 In the final parent and practitioner event, co-designers were again referred to the developing
4 PATH model and asked to deliberate remaining discussion themes and revisit any constructions
5 requiring further clarification. Participants were then presented with six SHE advice areas and
6 related components identified from the earlier scoping review: sleep timing, bedtime routines,
7 communication adaptations, environment, behaviour management and physiological factors. As
8 a group they were asked to report on their views regarding the acceptability of SHE advice and
9 how implementation should be supported. This concluded the co-design events.
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18 **Data analysis**

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21 All events were audio taped and video recorded for the purposes of verbatim transcription and
22 data were thematically analysed (Braun and Clarke, 2006) in relation to the six discussion
23 themes (Table 2). Data were coded to identify repeated debates of topics related to each
24 discussion area. Co-designer's comments from each event which indicated agreement or
25 disagreement with existing findings and any new constructions or priorities for sleep service
26 improvement were sequentially recorded separately on the developing PATH model.
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34 Trustworthiness was demonstrated through member checking (Burnard et al., 2008) of findings
35 by co-designers, triangulation through adopting multiple data collection methods, and keeping a
36 clear evidence trail throughout the co-design process. Scoping review, exploratory and co-
37 design study findings were synthesised to iteratively develop a SHE tool, programme theory and
38 explanatory logic model which were scrutinised by the research team. Analytical correlations
39 were also made with mid-range (research based) and novel theories of change to demonstrate
40 the nature of complexity embedded in a SHE intervention for children with DD.
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53 **Findings.**

SHE tool development.

A SHE tool incorporating six advice areas and 45 individual components for sleep practitioners to select from, was developed from synthesising scoping review and co-design study findings (Table 5). Advice components were included if they were supported by a minimum of two scoping review citations or one citation plus additional research evidence or co-designer agreement, to ensure tool validity.

[Table 5 to be inserted here] SHE tool for children with DD.

Programme theory development.

This study developed a programme theory to underpin the SHE tool. This was visually represented as an outcomes chain logic model (Figure 3), which is circular to emphasise the holistic approach and the cyclical rather than linear process of the intervention. The theory of change is illustrated by the blue boxes in the diagram's centre, depicting each of the intervention's outcomes. The lightest blue boxes represent the immediate outcomes, mid-blue boxes represent intermediate outcomes and the final two darkest blue boxes show the ultimate outcomes of SHE. Outcomes are graded (focused and scoped) in terms of how much they can be directly attributed to the intervention, to ensure programme results are not under or over-claimed and intervention complexity is not overlooked.

Typically, parents and practitioners begin at the 'Parents and practitioners have a shared understanding of what a sleep problem is' outcome and move in a clockwise direction achieving

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3 intermediate and ultimate outcomes (as represented by the black arrows- intended progression
4 of outcomes). The mechanisms by which each outcome is achieved are explained in the theory
5 of action (available by contacting authors) represented in the first encompassing purple ring,
6 which incorporates: success criteria, programme factors, non-programme factors, activities
7 processes and principles, resources and inputs (financial and human) outputs and throughputs
8 (Funnell and Rogers, 2011). However, parents may backtrack to previously attained outcomes
9 or exit the intervention at various time-points and after a period of time re-join at the stage of
10 'Parents and practitioners have a shared understanding of what a sleep problem is'. To
11 represent this, red arrows show how outcomes are sometimes not achieved as originally
12 intended, due to contextual factors (programme and non-programme factors) and the
13 intervention fails or takes longer to work.
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27 **[Figure 3 to be inserted here] SHE programme theory- outcomes chain logic model.**
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33 Emerging conceptualisations with mid-range theories of change - Self-efficacy, Empowerment,
34 Normalisation and the Trans-theoretical model (TTM) of change- are depicted in the green ring.
35 Novel analytical themes -legitimation, customisation, knowledge sharing, health expectation
36 and rationing and gaming- are denoted in the outer yellow ring. Both rings encapsulate the
37 theory of change and action to show how they have relevance across all outcomes.
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47 **Application of mid-range theories of change.**

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50 **Self-efficacy theory.**

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53 Findings showed how parents' ability to both recognise children's sleep problems and engage
54 with SHE, was affected by the attitudes and support of others. This links with self-efficacy theory
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3 (Bandura, 1977; 1997) which holds that people with a strong sense of self-efficacy frequently
4 achieve success, whereas those who doubt their capabilities yield when faced with challenges.
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6 In the 'Parents and practitioners have a shared understanding of what a sleep problem is'
7
8 outcome, the contextual factor was identified of parents' partners and relatives needing to
9
10 concur on sleep problem existence. Co-designers acknowledged how wider family members
11
12 sometimes adopted stoic attitudes towards children's sleep difficulties, making it harder for
13
14 parents to publicly acknowledge them. This chimes with the self-efficacy building strategy of
15
16 'social persuasion' whereby individuals who receive encouragement often achieve positive
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18 outcomes:
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23 *"It took some convincing with my husband, you know that we had a problem in the first*
24 *place because, in his parent's generation, it goes under the carpet you forget about it, it*
25 *doesn't exist, well I'm sorry but it does."* (Parent).
26
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30 In the 'Regularity and quality of child's sleep improves' outcome, links were made with other
31
32 main strategies which build self-efficacy. The activity of motivating parents to measure
33
34 improvements by completing sleep outcome measures chimes with 'mastery experiences' which
35
36 holds that success is achieved through perseverance. Also, the contextual factor of practitioners
37
38 acknowledging the readiness and capacity of parents to engage with SHE advice, relates to the
39
40 strategy of 'modifying individual's perceptions of their physical and emotional states'.
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46 **Empowerment theory.**

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49 Findings showed how parents wanted to be empowered to identify their children's sleep
50
51 problems, access sleep services, and take an active role in assessing sleep problem causes.
52
53 This espouses the tenants of empowerment theory which encompasses self-determination and
54
55 participation, and posits that problems are best addressed by those experiencing them (Perkins
56
57

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3 and Zimmerman, 1995). In the 'Parents and practitioners have a shared understanding of what
4 a sleep problem is' outcome, the screening activity was identified of parents having the option of
5 referring to a sleep checklist in their Personal Child Health Record (PCHR) or hand held 'Red
6 Book'. Parents posited they should be well informed of sleep expectations and be able to
7 promptly identify sleep problems independently using the familiar PCHR. This demonstrated
8 parents need to be active participants, taking ownership of their child's health rather than
9 passive or powerless recipients of care:
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18 *"More pages within the red book to ask you or make you do your own analysis of*
19 *is your child up to scratch?" (Parent)*
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26 The outcome of 'Sleep services are well publicised and accessible for parents' included
27 activities which required sleep services to actively publicise themselves via the internet, posters
28 and leaflets. Co-designers reported that sleep teams were often poorly advertised, creating an
29 unnecessary barrier for parents who were motivated to seek support. Parents wanted to be
30 empowered to independently source professional sleep help, which could be facilitated by sleep
31 services raising their public profile:
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39 *"We need more promotion that there is help available." (Parent).*
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45 **Normalisation theory.**

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47 Findings showed how parents expressed a need for 'normalcy' when addressing their children's
48 sleep problems and desire not to feel different from other parents of typically developing
49 children. This chimes with the tenants of normalisation theory (Gilbert, 2004; Wolfensberger and
50 Tullman, 1982), which devalues difference and regards it as deviant, causing stigmatisation and
51 social exclusion. In the outcome 'Parents and practitioners have a shared understanding of what
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1
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3 a sleep problem is', the success criteria of ensuring all children were screened for sleep
4 problems was identified. Co-designers agreed sleep practitioners should ask ALL parents about
5 sleep whether their child had a DD or not. It was important for parents not to feel different from
6 others when they embarked on the process of accepting there might be a problem with the way
7 their child slept:
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13
14 *"It's got to be the norm(..) you don't feel like you are being singled out especially"*

15
16
17 (Parent).
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21 In the outcome 'sleep services are well publicised and accessible for parents', the success
22 criteria of parents sourcing sleep help through a generic sleep service was posited which links
23 with a desire for sameness and normalisation principles. Parents described how it would be
24 easier to approach a mainstream rather than specialist service as a first point of call for sleep
25 help.
26
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31
32 *"Why does it need to be different? (..) Kids could just have a sleep issue, that*
33 *could be their only issue I don't understand why you have to have*
34 *separate."*(Parent)
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41 However, some co-designers disagreed with mainstreaming sleep service provision arguing that
42 the specific needs of children with DD could be overlooked:
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45
46 *"It's the worse thing for parents I think would be going to a generalist sleep advisor and*
47 *then having explain what the condition the child has ."* (Parent)
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51 **Stages of change theory (Transtheoretical model).**
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3 Findings indicated that parents often go through distinct stages of change in their journey
4
5 towards improved sleep, which broadly links to the transtheoretical model (TTM) of change
6
7 (Prochaska and DiClemente, 1983; Prochaska and Velicer, 1997). This model centres on the
8
9 principle that behaviour change is temporal and structured firstly by behavioural intention
10
11 (thinking and planning for change), action, maintenance (behaviours sustained for six months)
12
13 and termination (fully established behaviours).
14
15

16
17 Outcomes of 'Parents and practitioners improve their understanding of the sleep problem' and
18
19 'Regularity and quality of child's sleep improves' link to the action stage whereby parents
20
21 actively engage with sleep problem assessment and making changes to sleep hygiene
22
23 practices.
24
25

26
27 *"After the assessment we have a specific session, we have it all out on a piece of*
28
29 *paper yer, draw it all out (..) we want them to try and put it together like a jigsaw."*
30

31 (Practitioner)
32
33

34
35 Progression to the outcome of '*Quality of life improves for the family*' also abstracts to the
36
37 maintenance stage where sleep improvements are sustained and the family experiences
38
39 positive follow-on effects. This outcome incorporates the success criteria which highlights how
40
41 parents need to feel supported to maintain progress via parent support groups.
42

43
44 *"Parents need to know that there is this group, this group that and the other out*
45
46 *there just so they can go "arggh!". That is really important."* (Parent)
47
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51 **Application of novel analytical themes.**

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53 **Legitimation**

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3 Constructions throughout the programme theory demonstrated stakeholders' perceptions of how
4 children's sleep problems were under-valued and viewed as a private parenting issue by
5 parents, practitioners, policy makers and wider society. It is posited that increasing the
6 legitimacy of sleep problems is a foundation upon which SHE implementation needs to be
7 based. For example, in the outcome 'Parents and practitioners have a shared understanding of
8 what a sleep problem is', contextual factors of parents stoically coping with sleep problems and
9 struggling to give precedence to sleep against competing health issues, demonstrate the
10 influence of legitimacy on help seeking behaviours:
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21 *"It's not always going to be the first thing on your mind when you are trying to battle for*
22 *lots of other things."* (Parent)
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29 To address this, co-designers made recommendations to legitimise sleep problems in the minds
30 of parents, practitioners and wider society through increasing the public conversation about
31 sleep and running national sleep screening initiatives and media campaigns to promote
32 understanding. Co-designers also showed how they also perceived funders currently poorly
33 prioritised sleep problems in children with DD, across all outcomes. This was linked to a lack of
34 legitimacy afforded to the issue of children's sleep. Stakeholders reflected this in their requests
35 for better financial resourcing of sleep teams to meet service need, provide continuity of
36 parental support, produce comprehensive sleep assessments and champion parent support
37 groups.
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48 *"I have tried to get him some help and nobody has ever mentioned any services (..)A lot*
49 *of services always tell you they've got no money, it's not your fault is it?"* (Parent).
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55 **Customisation**

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3 Findings make explicit the need to customise SHE advice according to assessed need, rather
4 than giving poorly informed or standardised advice. It is posited that if parents perceive advice is
5 tailored, they will feel motivated to follow it which positively impacts on implementation success.
6
7 Customisation is defined within the broader context of healthcare as a shift away from
8
9 standardisation to being responsive to the individual needs of patients/service users (deBlok et
10
11 al., 2012; Minvielle et al., 2014). The notion of customisation is linked throughout the outcome of
12
13 'Parents and practitioners improve their understanding of the sleep problem'. Activities such as
14
15 sleep practitioners performing multiple assessment sessions, at the child's home, at bedtime
16
17 and involving other members of the multidisciplinary team and partner organisations in the sleep
18
19 assessment show how SHE should be carefully considered and personalised to family need.
20
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23

24
25 *"Sometimes there's not enough information gained before things are put into practice*
26
27 *that might not actually be right for that family."* (Parent)
28
29

30 In the 'Parents and practitioners develop a safe and supportive relationship' outcome, the
31
32 success criteria of 'Parents should receive the amount of support they need throughout their
33
34 contact with sleep services' also demonstrates the impact of customisation in successful SHE
35
36 implementation. Co-designers reported how sleep services sometimes fell short of parent's
37
38 expectations in terms of frequency and duration of support:
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41 *"I didn't see her as many times as I would have liked to (..) I'm trying to get her*
42
43 *back."*(Parent)
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49 **Knowledge sharing**

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52 Findings make explicit the nature of knowledge sharing within SHE, which is defined as a two-
53
54 way knowledge exchange between care providers and recipients of care that increases patient
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3 involvement and enhances positive outcomes (Davis and Meltzer, 2007; Tobiano et al.,
4 2016). Co-designers made the recommendation of employing a paid parent buddy to share their
5 knowledge with parents in the 'Regularity and quality of child's sleep improves' outcome.
6
7 However, one practitioner questioned the acceptability of this, indicating how the role could be
8 perceived as threatening:
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14 *"Would it not be an idea to have parent experts? Paid parents? (..) Frankly who*
15 *has experience, who has actually been paid to do that. My point is they never*
16 *give it the value that it deserves."* (Parent)
17
18

19
20
21 *"I still think that to pay for someone to mediate shouldn't that money be better*
22 *spent training professionals on how to build that relationship and how to*
23 *behave?"* (Practitioner)
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32 Knowledge exchange processes that focused on the responsibilities of sleep practitioners to
33 freely share their expertise with parents were also identified in the ultimate outcome of
34 improving children's sleep. For example, the process of delivering psycho-education to
35 rationalise SHE advice was suggested by practitioners as a mechanism that could help support
36 implementation; although parent co-designers did not report any first-hand experience of
37 receiving this.
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45 *"I think just knowing(..) just finding out the reasons behind something can just put*
46 *yourself at ease then, okay it doesn't get rid of the problem, but it puts yourself at*
47 *ease then and you can start building on that."* (Practitioner)
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52 **Health expectation**

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3 Findings demonstrate the added complexity of health expectation which holds that parents need
4
5 to feel hopeful that their child's sleep can improve. Janzen et al. (2005) define a health
6
7 expectation as a prediction relating to the effects of health behaviours on the psychological
8
9 status of the body and suggest that expectations are highly important to the experience of
10
11 health and health care. Data showed how low health expectations can impact on sleep problem
12
13 recognition and when practitioners began with a negative outlook this invoked feelings of
14
15 hopelessness in parents at the start of their SHE journey:
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19 *"With the GPs it was 'it's just the way he was' and I don't like that attitude it's just the*
20
21 *way he was"* (Parent)
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24 Data also indicated how it is important to maintain parents' hope that sleep can improve during
25
26 SHE implementation and that practitioners need to adopt an enduring reassuring attitude, to
27
28 encourage parent's conviction in their abilities to effect change:
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31 *"She did it very positive (..) it kept him [son] hoping"* (Parent)
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34 **Rationing and gaming**

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37 Findings make explicit how the adoption of rationing and gaming strategies by sleep teams can
38
39 affect implementation success. Such strategies are often employed by organisations when they
40
41 change their behaviour to affect the results they report, as these will be used to control them
42
43 (Bevan and Hood; 2006). It is posited that health (and social service) sleep teams reduce the
44
45 accessibility of their service, to deter excessive referrals and keep waiting times or referral to
46
47 treatment times within acceptable targets. In the 'Sleep services are well publicised and
48
49 accessible for parents' outcome, it was recommended that sleep teams offer an open access,
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51 fully inclusive service for children aged 0-18, with any DD and with a broad geographical
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53 coverage. Co-designers suggested this in response to experiences of restrictive and complex
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3 entry processes to sleep teams, which had a negative impact on families trying to source
4 support.
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11 *“Some families seem to fall through the net as well they don’t fit this criteria.”*

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13 (Practitioner)
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19 Discussion

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22 The findings from this study enhance our understanding of how SHE is expected to work to
23 improve sleep in children with DD. Abstracting programme theory to evidence based theories of
24 change demonstrated how the intervention offers plausible solutions to sleep problems. The
25 process encouraged critical reflection of programme theory; for example making analytical links
26 with self-efficacy theory highlighted the potential for exploring in greater depth, strategies for
27 building parent’s self-efficacy and incorporating them into the intervention. In addition, making
28 links with normalisation theory strengthened rationale for constructions presented. For example,
29 it was posited that parents were often fearful of accessing specialist sleep services and stepping
30 into disabled services, which was associated with a notion that difference was undesirable and
31 something to be anxious about. Similar findings were shown in studies by Vogel and Wade
32 (2009) and Dempster, Wildman and Keating (2013), which showed the need to consider stigma
33 in service design, to ensure those who needed advice were supported to access it in a timely
34 manner. Co-designers suggested a generic sleep service entry point for SHE to normalise
35 seeking sleep help, however, some argued that generic practitioners may overlook the child’s
36 individual disability needs which links with established criticisms of normalisation that
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3 emphasise its denial of difference and value of conformity (Culham and Nind, 2003; Gilbert,
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5 2004).
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11 There were however, limitations in the application of mid –range theories of change. For
12
13 example, applying the tenets of empowerment theory to all parents was problematic, as it could
14
15 not be assumed everyone had the desire or capacity to play an active role in addressing their
16
17 children’s sleep problems. Programme theory accounted for this complexity by acknowledging
18
19 how parents may not have the time, strength or literacy to engage and how practitioners needed
20
21 to accommodate these contextual factors. In addition, whilst abstraction to the TTM of change
22
23 was useful to help describe the different stages at which parents enter and move through a SHE
24
25 programme, it was difficult to neatly match each outcome with each change stage because in
26
27 reality parents and practitioners varied in their time spent achieving each outcome. This reflects
28
29 a popular criticism of the TTM which argues that the categorisation of change into a series of
30
31 distinct stages rather than a continuous process can be unrealistic (Armitage, 2009; Nigg et al.,
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33 2011). Therefore, whilst the process of making analytical links with mid-range theories
34
35 encouraged critical reflection of programme theory, applicability issues meant they were viewed
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37 as heuristic devices rather than strict formulas to adhere to.
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45 This study also provides an explicit understanding of the nature of the complexity embedded in
46
47 a SHE intervention for children with DD. Findings show children’s sleep problems need to be
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49 given enhanced legitimacy and demonstrate how this impacts on parent’s help-seeking
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51 behaviours. Concordance is found with Robinson and Richdale’s (2004) exploratory study which
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53 concluded that “many parents are poor at recognizing that a sleep problem exists. Treatment is
54
55 frequently not sought even if the problem is recognized” (p.149) and attributed this to parents’
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3 knowledge of parenting and beliefs around sleep. Wiggs and Stores (1996) similarly reported
4 reluctance from parents to seek help which they linked to stoicism and a belief they could carry
5 on without professional help. Wider literature therefore, supports the premise that parents need
6 to be encouraged to give more value and currency to children's sleep problems to ensure they
7 receive appropriate help.
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14 Findings also showed the need to give greater legitimacy to children's sleep problems to ensure
15 adequate service provision. . This concurs with the Tired all the Time report (Family Fund, 2013)
16 which reports that "sleep difficulties need to be given a higher priority by health, education and
17 social care professionals and listed in the local offer (England)" (p.13). In reflecting on why sleep
18 problems children with DD are poorly prioritised by organisations and policy makers, Beresford
19 et al. (2012) point to the fact children with DD "are a small minority in a much larger population.
20 Thus, there is a risk of them being overlooked by mainstream parenting activities at a local
21 level" (p.271). Broad links can also be made with reports which have demonstrated how people
22 with learning disabilities are a marginalised group who receive inequitable and inadequate
23 healthcare (Atkinson et al., 2013; Department of Health, 2015; Disability Rights Commission,
24 2006; Emerson et al., 2012; Mencap, 2007). Therefore, the minority status of children with DD
25 could explain why their sleep problems may go unnoticed by policy makers. It is also posited
26 that the 'invisibility' of sleep problems to others outside the family home, may result in
27 organisations placing less priority on the need for professional input. In contrast to other health
28 issues (such as challenging behaviour or continence issues), sleep problems largely occur at
29 bedtime or during the night, so their immediate impact is limited to the family. Reports that show
30 how generic practitioners still need to treat parents of people with DD with greater respect and
31 value their caring role (Department of Health, 2009; British Institute of Learning Disabilities
32 (BILD), 2013) indicate how this explanation of "out of sight, out of mind" may be correct.
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3 This study makes explicit the need to customise SHE advice according to assessed need,
4 rather than giving poorly informed or standardised advice, which implies a training need for
5 sleep professionals. It is posited that if parents perceive advice is customised, they will feel
6 motivated to follow it; positively impacting on implementation success. Parallels can be drawn
7 with the personalisation agenda which shifts service provision away from a service led to a
8 person centred ethos (Black et al., 2010; Davis and Gavidia-Payne, 2009; Mansell and Beadle-
9 Brown, 2004) and the principles of prudent healthcare (Bradley and Willson, 2014) which holds
10 that patients should receive the minimum appropriate intervention to achieve health outcomes.
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14 This study also makes explicit the nature of knowledge sharing within SHE. Employing
15 experienced parent buddies to support implementation was largely supported by co-designers,
16 but conflict around practitioner acceptability existed. This concurs with broader literature
17 examining the role of lay health workers which highlights implementation issues such as role
18 confusion and call for the adequate conceptualisation of this role (Glenton et al., 2013;
19 Kennedy, Milton and Bundred, 2008). Furthermore, the knowledge sharing recommendation of
20 psycho-education, is supported by (Beresford et al., 2016) who also found that increasing
21 parental knowledge about sleep was instrumental improving children's sleep.
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24
25 The complexity of how low health expectation can negatively impact on sleep problem
26 recognition and active engagement with SHE was also demonstrated. This concurs with wider
27 evidence which reflects how parents and practitioners often perceive sleep problems in children
28 with DD to be inevitable and untreatable (Family Fund, 2013; McDougall, Kerr and Espie, 2005;
29 Robinson and Richdale, 2004; Wiggs and Stores, 1996). Parallels can also be drawn with the
30 'diagnostic overshadowing' bias whereby a person's underlying health needs are overlooked
31 and attributed to their learning disability (Mason, 2007; Mason and Scior, 2004). Furthermore,
32 calls for practitioners to raise their health expectation of individuals with learning disabilities to
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3 ensure equitable care have also been demonstrated in recent reports (Department of Health,
4 2015; Disability Rights Commission, 2006; Mencap, 2007).
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8 Finally, this study shows how implementation success is affected by sleep services adopting
9 rationing and gaming strategies to manage scarce resources and meet performance targets. It
10 is purported that such strategies can mask the true level of service need; an implication mirrored
11 by Stores and Wiggs (2001) who suggest “services will not improve until a demand for better
12 provision is felt”(p.6). Concordance is also found with policy guidance that calls for enhanced
13 accessibility and clear referral routes to sleep services for children with DD (Family Fund, 2013;
14 NHS England, 2015).
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24 **Conclusion**

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27 Study findings have highlighted a range of implications for policy, practice and research as
28 follows:
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32 **Policy:**

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35 There is a need for:

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38 ● National sleep screening initiatives, media campaigns spreading positive messages
39 about sleep, re-prioritisation and adequate resourcing of sleep service provision to foster
40 a climate of positive health expectation and ensure children’s sleep problems are
41 legitimised.
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46 ● Enhanced understanding of how the customisation of SHE fits in with prudent healthcare
47 and personalisation agendas.
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51 ● Greater awareness of the implications of rationing and gaming practices and
52 commitment to improve parents’ experiences of accessing professional sleep support.
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55 **Practice:**

- Adequate sleep training for practitioners, so they can fully understand sleep problems, customise SHE and deliver psycho-education.
- More parental involvement in sleep assessment and decision making processes to facilitate knowledge exchange.
- To embed psycho-education into SHE interventions to facilitate knowledge exchange
- To champion parent support groups to ensure parents are supported with SHE implementation.

Research:

- Continued research into the experiences of families, to ensure children's sleep problems are afforded enhanced legitimacy and are current in the minds of policy makers.
- Research to conceptualise the paid parent role within SHE implementation to further develop the emerging discipline of lay helping within care.
- Piloting and feasibility work to ensure the SHE intervention can be carried out as intended, before a main evaluative study can be designed.

Declaration of conflicting interests

The Author(s) declare(s) that there is no conflict of interest.

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3 [1] In all events the term sleep advice was used instead of SHE to ensure lay understanding.
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For Peer Review

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5 Table 1: **Operational definition of developmental disabilities (DD)**. (This has been
6 specifically developed for the purposes of this study and encompasses a variety of
7 neurological conditions).
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12 Conditions originating in the developmental period (0-18 years) including
13 specific learning difficulties, global developmental delay and disorders of
14 psychological functioning such as Autistic Spectrum Disorder (ASD)
15 (encompassing Autism and Asperger syndrome). Excludes children with
16 a sole diagnosis of physical disabilities.
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Table 2: **Six co-design study discussion themes.**

1. Parents and practitioners have a shared understanding of what a sleep problem is.
2. Sleep services are well publicised and accessible for parents.
3. Parents and sleep practitioners develop a safe and supportive relationship.
4. Parents and sleep practitioners improve their understanding of the sleep problem.
5. Regularity and quality of child's sleep improves.
6. Quality of life improves for the family.

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Table 3: Parent participant characteristics

Parent number	1	2	3	4	5	6	7	8
Child's age	9	14	7	12	7	8	16	14
Child's gender	Male	Male	Male	Male	Male	Male	Male	Male
Child's diagnosis	Learning disabilities	ASD	ASD	ASD	ASD	ASD	ASD	ASD
Parent participation in co-design event 1/ 2/ 3.	1 & 3	1, 2 & 3	1 & 2	1 & 3	1	1	1, 2 & 3	3

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Table 4: **Sleep practitioner participant characteristics**

Practitioner number	1	2	3	4	5	6
Practitioner role.	FSO	SP	DO	DO	DO	DO
Team type	SCT	VO	VO	VO	VO	VO
Co-design event participation: 2/ 3.	2 & 3	2 & 3	2	3	2	3

KEY:

FSO- Family support officer

SP- Sleep practitioner

DO- Development officer

SCT- Social care team

VO- Voluntary organisation

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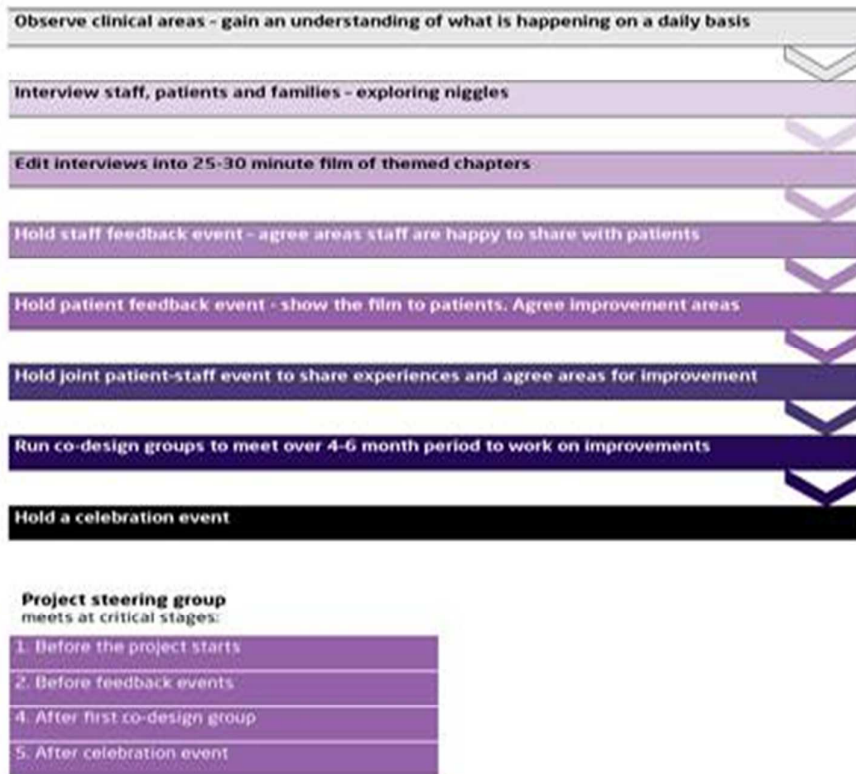
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Table 5 SHE tool for children with DD

1.Sleep timing	2.Bedtime routines	3.Behaviour management	4.Environment	5.Physiological	6. Communication adaptations
1.1. Set consistent bedtimes and wake times (including holidays and weekends)	2.1.Set relaxing routine	3.1. Ensure bedroom is not used a punishment setting	4.1. Ensure quiet noise levels at sleep times	5.1. Encourage healthy diet, limit fat and sugar intake.	6.1. Give clear expectations, prompts and cues.
1.2. Set age appropriate bedtimes	2.2. Discourage television or blue light emitting devices at bedtime. (consider blue light blocker sunglasses if resistant)	3.2. Avoid soothing to sleep with a bottle/breast after 6-12 months old. (#care re: weaning/feeding difficulties)	4.2. Consider room temperature 16-20c, bedding and sleep clothes to maintain comfortable body temperature	5.2. Encourage daily exercise (but avoid this late evening)	6.2. Incorporate augmentative communication strategies
1.3. Encourage age appropriate daytime napping	2.3.Consider alternative therapies and relaxation techniques	3.3. Incorporate rewards which are meaningful to the child.	4.3. Ensure a darkened bedroom (black-out blind)	5.3. Ensure child has plenty of light in the day	6.3. Encourage routine timing of all meals.
1.4 Avoid late afternoon napping	2.4. Limit bedtime rituals	3.4. Set and stick to limits	4.4. Ensure bedroom has a familiar layout and calm decoration.	5.4. Avoid smoking and alcohol	6.4. Consider visually modelling routine using a doll.
1.5 Avoid excessive time in bed	2.5 Ensure routine activities are consistently ordered and timed	3.5. Ensure child falls asleep and sleeps alone in own bed	4.5. Allow security object to promote self-soothing	5.5. Light meals only near bedtime.	6.5 Ensure bedroom is only used for sleep and calm activities.
	2.6. Ensure routine is 20-45 minute duration	3.6. Put child to sleep drowsy	4.6. Consider sensory sensitivities of the child	5.6. Limit caffeine intake	
		3.7.Give minimal interactions during night time feeds and night awakenings	4.7. Ensure bed is comfortable (consider sleep systems)	5.7.Ensure child uses toilet before bed	
		3.8.Encourage child to think about problems/plans before going to bed	4.8. Remove or hide stimulating toys in bedroom	5.8. Encourage milk and eat tryptophan/melatonin rich foods with complex carbohydrates at supertime.	
			4.9.Use nightlight or red modelling bulb if preferred	5.9. Ensure child's individual hydration needs are met	
				5.10. Avoid blackcurrant juice in the evenings	

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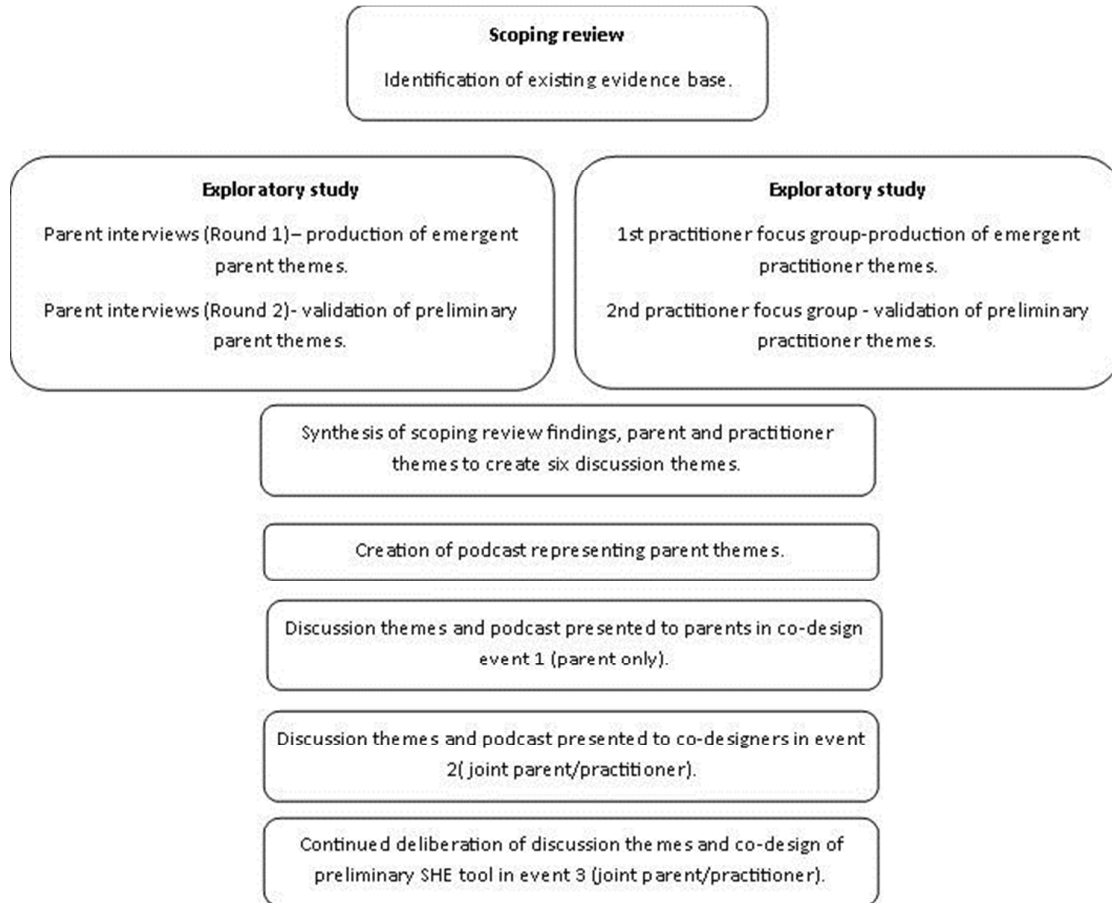
Figure 1 **Experience based co-design (King's Fund, 2014).**

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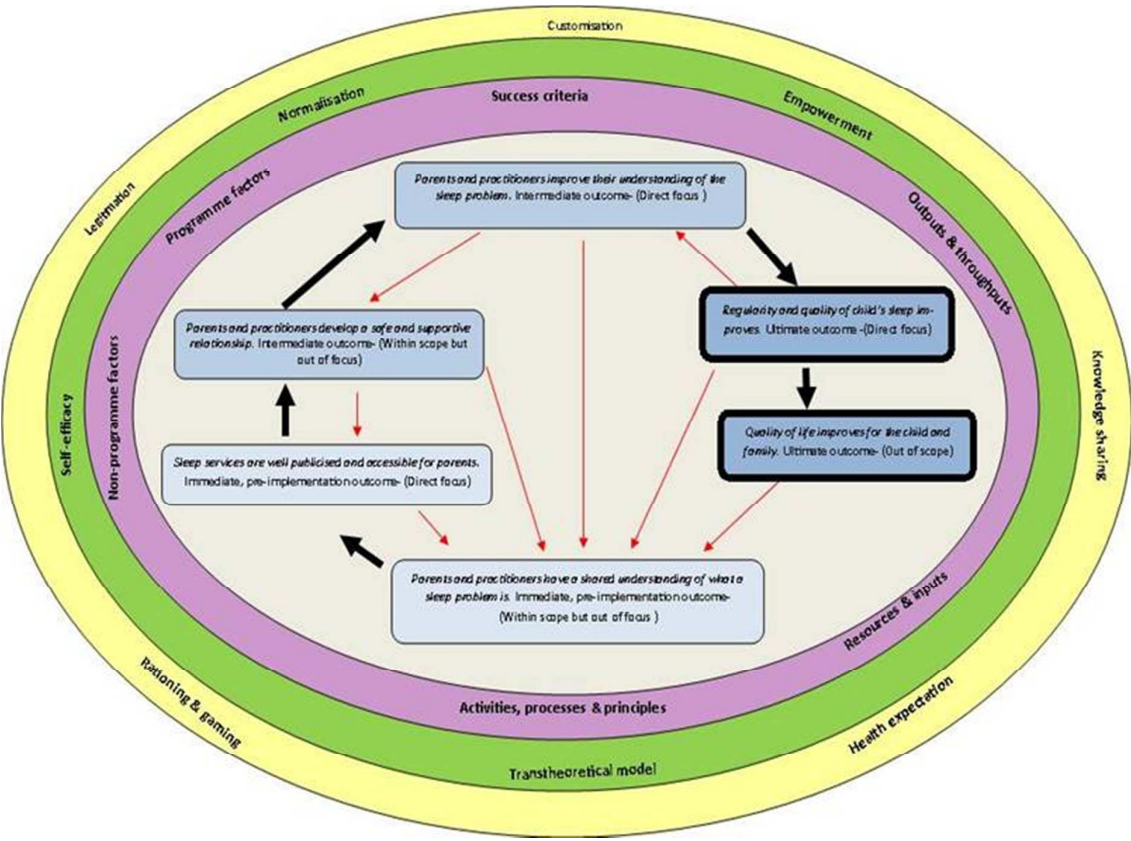
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[Figure 2 to be inserted here] Overview of adapted co-design method.



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KEY:
Outcomes (theory of change)
Black arrows- intended progression
Red arrows- unintended movement
Theory of action
Mid-range theories
Novel analytical themes

Figure 3: SHE programme theory- outcomes chain logic model. Author 1

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