Sleep Hygiene Education and Children with Developmental Disabilities: Findings from a Co-Design study.

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So what?!//

Sleep problems in children with developmental disabilities (DD).

- Sleep problems affect around 80% of children with DD and are more common and severe than in typically developing children (Beresford et al., 2016; Jan et al., 2008).
- Significant impact on the child's already compromised cognitive development
- Negative impact on the child's behaviour, mood, social skills, physical health, mental health
- Negative impact on family life

What is sleep hygiene?

Good sleep hygiene is not….

Sleep hygiene education (SHE) definition

"A set of sleep-related behaviours that expose persons to activities and cues that prepare them for and promote appropriately timed and effective sleep."

(Jan et al., 2008, p.1344).

- SHE is an inadequately conceptualised intervention currently supported by theories based on popular wisdom.

- Professionals have routinely implemented SHE for years without explicit explanation of how the intervention works or what it is supposed to achieve.

- There is a need for evidence based and transparent SHE interventions, reflected in the prudent healthcare agenda which obliges professionals to only deliver care which is relevant to individual need -*"It would be an on-going process with most of them, trying different things seeing what worked."* Practitioner quote (scatter gun approach).

Research aim

- Aim to advance the knowledge base supporting SHE as an intervention for sleep problems in children with DD. To develop a systematic understanding about what SHE does, how it is delivered and how it is supposed to work to improve sleep- **programme theory**.

Research outputs

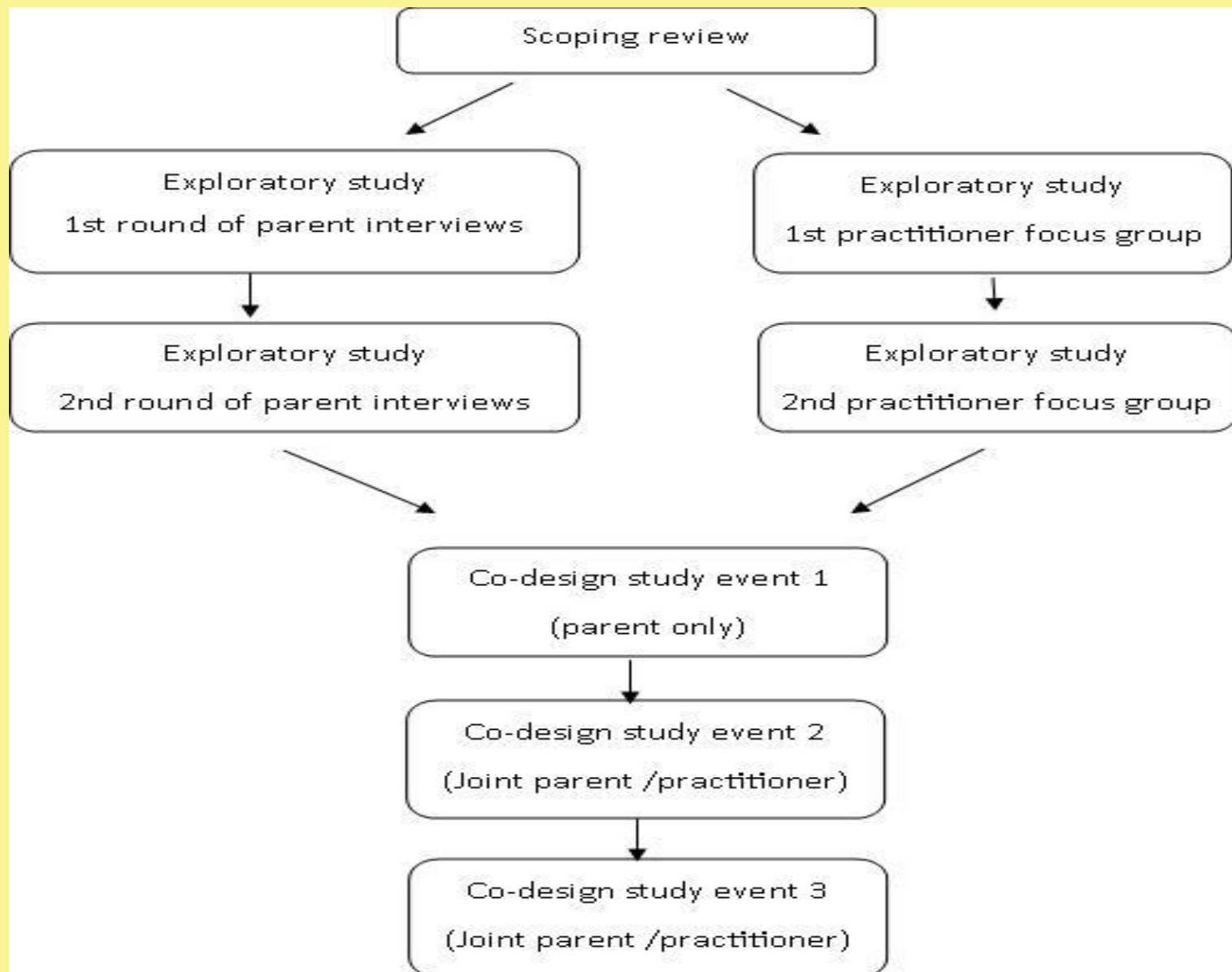- An evidence based SHE tool

  AND

- A nuanced **programme theory** communicating the essentials of SHE.

Theory of change- the core processes by which change occurs

Theory of action- how an intervention's activities stimulates these theories of change.
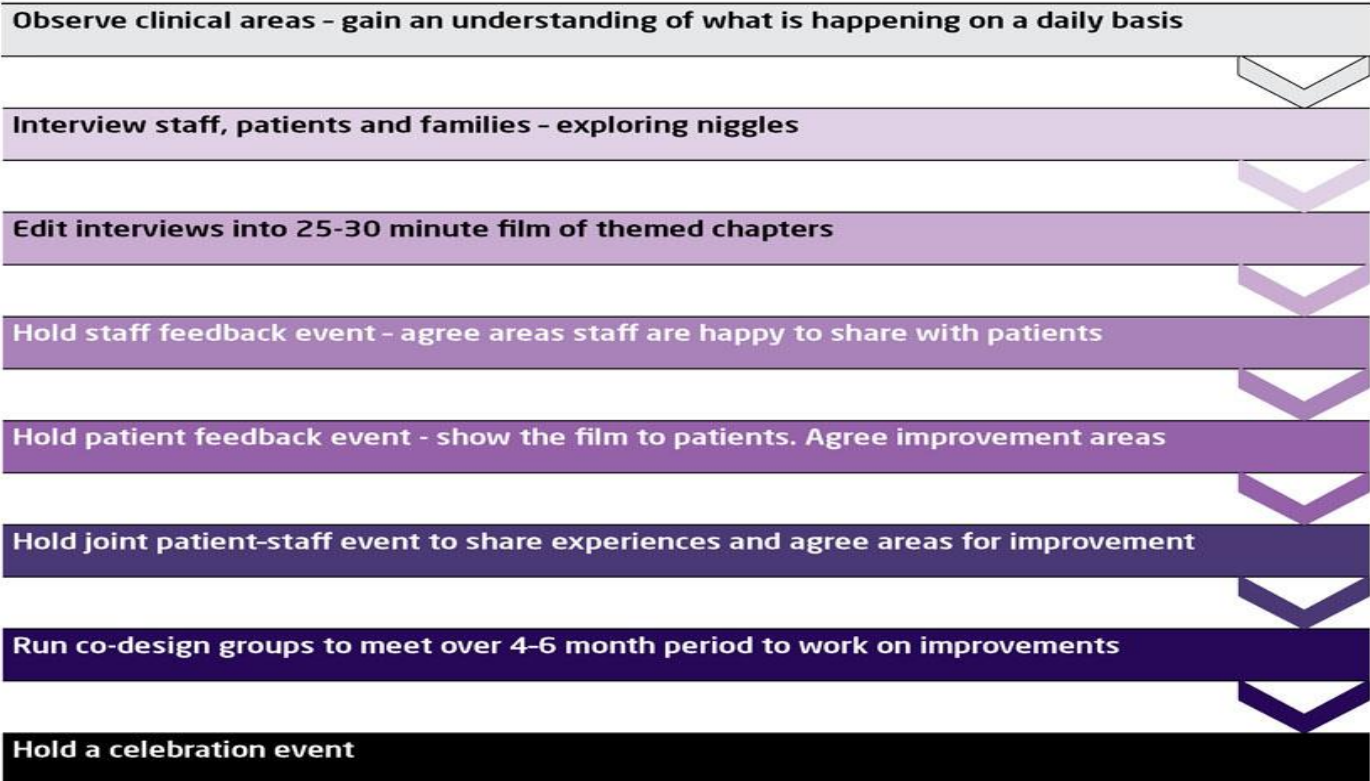
(Funnell & Rogers, 2011)

Overview of studies

Methodology

- The studies were guided by the Medical Research Council guidance for evaluating complex interventions (2000, 2008).

- Underpinned by a participatory methodology - research which is collaborative 'with' others as equal research partners, rather than 'on' them as subjects, and also incorporates an action agenda for reform that aims to improve individuals' lives. (Creswell, 2007).

- Experience based co-design (EBCD) (Kings Fund,2014)- a guiding qualitative method rooted in the principles of the participatory paradigm (adapted version).

Experience based co-design. Kings Fund (2014)

Observe clinical areas – gain an understanding of what is happening on a daily basis

Interview staff, patients and families – exploring niggles

Edit interviews into 25-30 minute film of themed chapters

Hold staff feedback event – agree areas staff are happy to share with patients

Hold patient feedback event - show the film to patients. Agree improvement areas

Hold joint patient–staff event to share experiences and agree areas for improvement

Run co-design groups to meet over 4–6 month period to work on improvements

Hold a celebration event

Project steering group
meets at critical stages:

1. Before the project starts

2. Before feedback events

4. After first co-design group

5. After celebration event

The co-design study

- In 2015, the co-design study brought together 8 parents of children with DD and 6 sleep practitioners as equal research partners to co-design a SHE tool and programme theory.

The co-design study

- These events began with 6 overarching themes developed at the conclusion of the Exploratory study:

- They were used as a flexible rather than constraining guide for debate, in line with a participative inquiry approach

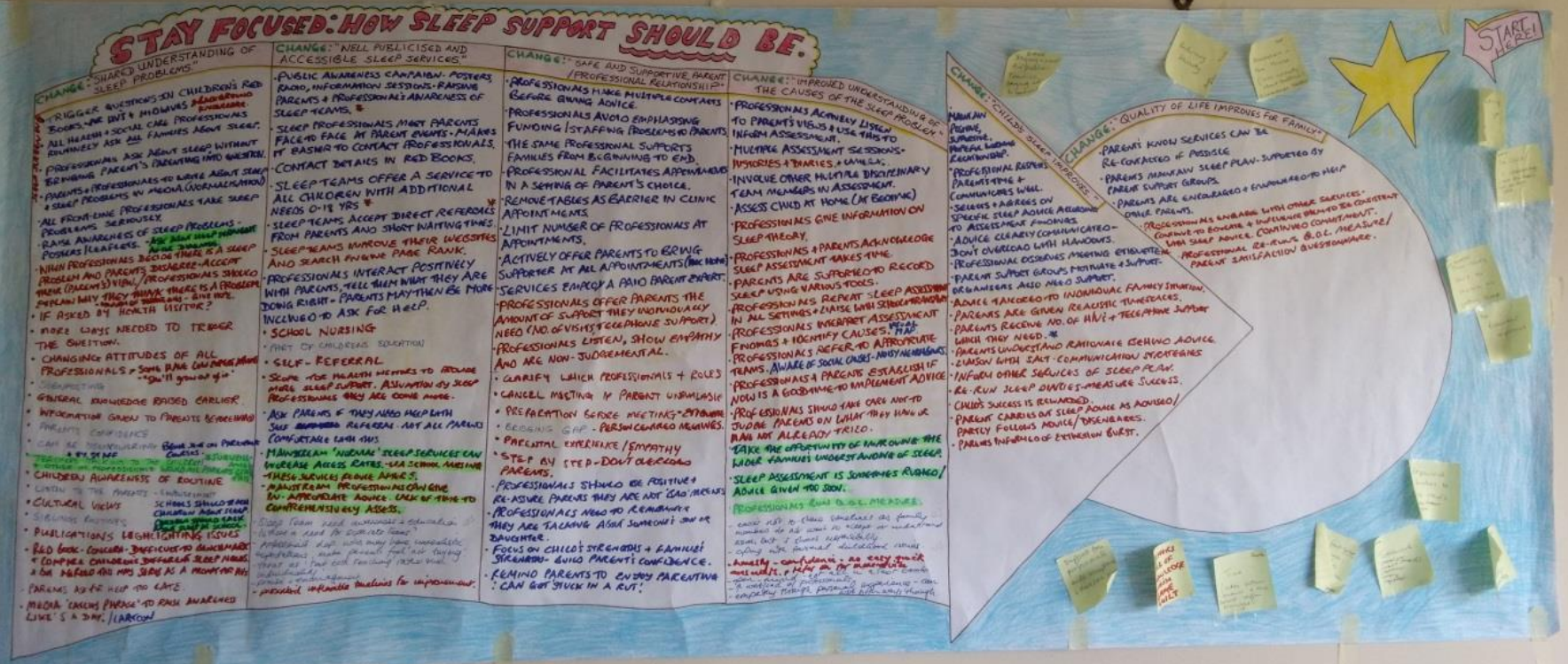| Overarching themes: |
|---|
| **1.**Parents and practitioners have a shared understanding of what a sleep problem is. |
| **2.**Sleep services are well publicised and accessible for parents. |
| **3.**Parents and sleep practitioners develop a safe and supportive relationship. |
| **4.**Parents and 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. |

The adapted Planning Alternative Futures with Hope (PATH) model

- The PATH model (Pearpoint, O'Brien & Forest, 1998) is a planning style which helps people to understand complex situations and take control over change (Sanderson & Lewis, 2012) and it was felt this mirrored a participatory approach.

- The basic principles of the PATH model were utilised.

- A wall sized model detailing the discussion areas and parents and practitioners ideas so far.

- Step 1- Required participants to dream and record how improved sleep would look like. They were then asked to imagine that they had achieved this and to describe how this felt.

- Focusing on the ultimate outcomes first (discussion areas 5 & 6) , energised the group and ensured the event began with a positive mind-set and clear shared vision.

- Participants were then asked to consider the start of their sleep journey and discussion area 1. This brought participants back to the present and required them to examine what life is like now. This created a tension between the existing problem and ultimate goals, and motivated the group to plan for change.

- Discussion areas 2, 3 & 4 were then debated in turn.

Adapted Planning Alternative Futures with Hope 'PATH' model (Pearpoint, O'Brien & Forest, 1998)

The SHE tool

- 6 domains: **Sleep timing, bedtime routines, behaviour management, environment, physiological and communication adaptations.**
- 45 individual components to select from.

# Developing the programme theory- *the theory of change.*

- In developing the theory of change, the 6 discussion themes were reframed as intended outcomes for a SHE intervention- represented as an outcomes chain.

Overarching 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.

The explanatory logic model

- The logic model visually represents the SHE programme theory (theory of change & action) and emerging conceptualisation of the study's original contribution to knowledge.
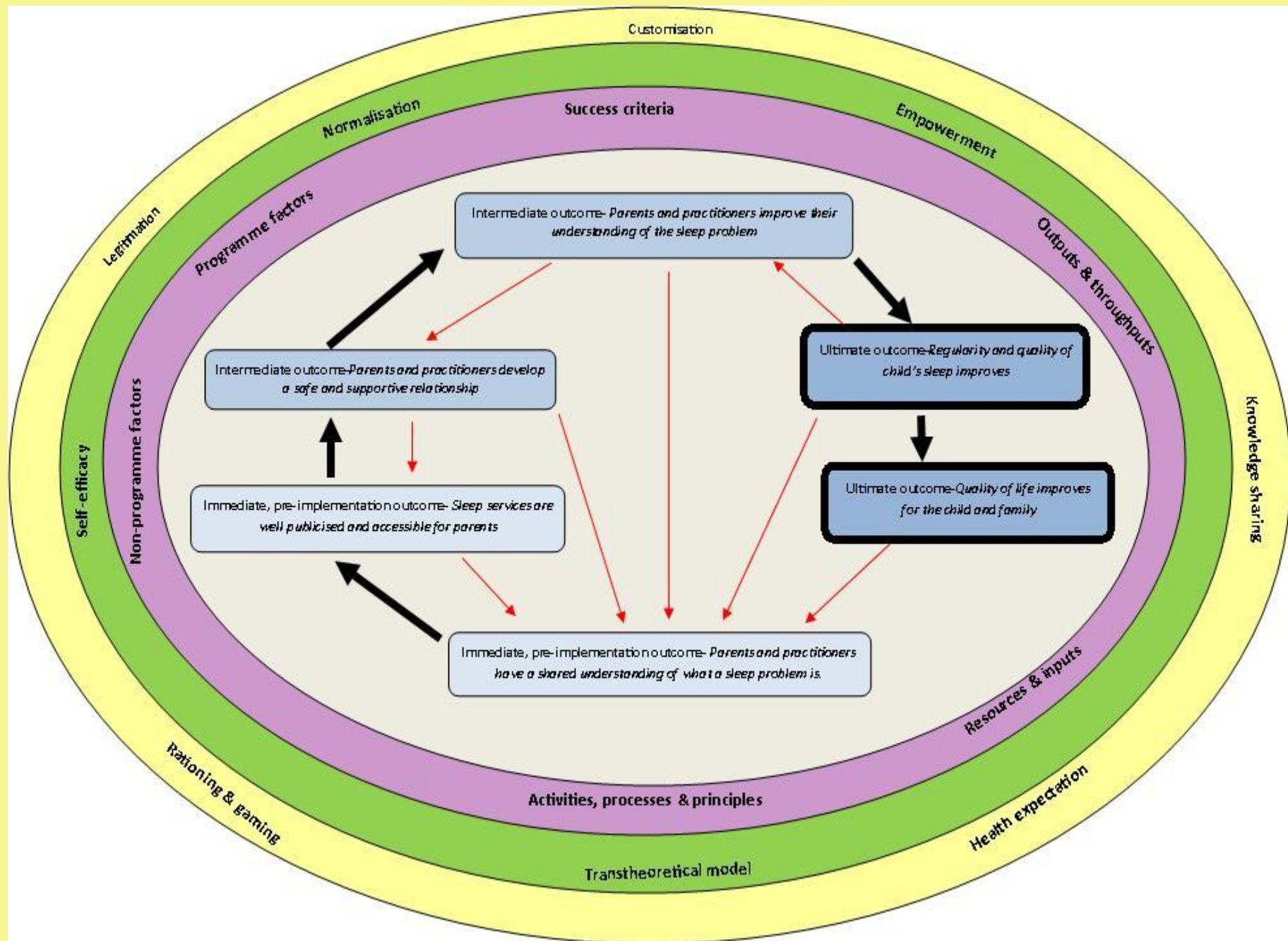
The original contribution to knowledge

"An explicit understanding of the complexity embedded in an SHE intervention. **Most importantly this study shows how the legitimation of sleep problems is a foundation on which SHE implementation should be based.** Findings also demonstrate a greater understanding of the nature of customisation, health expectation, knowledge exchange and impact of rationing and gaming on implementation success."

Legitimation

"*to make reasonable, sensible or valid*" Collins Dictionary (2016).

Constructions throughout PT demonstrated stakeholder perceptions of how sleep problems were viewed as a private issue by parents, practitioners, policy makers and wider society.

Increasing legitimacy of sleep problems can positively impact on implementation across all outcomes

Legitimation

- When parents do not view sleep problems as a justifiable concern, this impacts on their ability to acknowledge them and seek professional help.

- The extent to which practitioners legitimise sleep problems can influence parents' help seeking behaviours. They are sometimes dismissive.

- The extent to which society legitimises sleep problems can influence the pace at which parents recognise sleep problems and seek help.

"Because you accept its normal, you sort of think it's just part of them."
Parent.

"If they don't even give you any understanding you go away feeling "oh I shouldn't have come."
Parent.

"With the GPs it was 'it's just the way he was' and I don't like that attitude it's just the way he was"
Parent.

Customisation

Customisation represents a shift away from standardisation to being responsive to individual need (deBlok, Meijboom, Luijkx & Schols, 2012)

"Customisation is not totally absent in healthcare, but its link with the intervention it qualifies is often not explicit" Minvielle et al, 2014.

This study makes explicit the need for customisation and posits if parent perceive SHE is responsive to their family need, this will enhance implementation success.

Customisation

- Explicit links made to – multiple assessment sessions, at child's home, at bedtime involving MDT.

- Parents need to perceive practitioners have invested sufficient time before giving advice.

- Implies training need at a practice level

- Thesis findings show how parents value customisation.

- Links with principles of prudent healthcare (Bradley & Wilson, 2014) –minimum appropriate intervention rather than superfluous, poorly considered advice

"Not just one session, how they make conclusions about children based on 40 minutes."

Parent.

The community Paediatrician was almost patronising in terms of telling me.. we need to shower sort of.. no television, read him a story. Nobody sort of said 'Oh can we come out and monitor how he goes to sleep at night, or go through with you how you how you put a sleep routine together' ..... And maybe that could have helped."   **Parent**

Knowledge sharing

A two-way dialogue between practitioners and service users, rather than traditional monologue of information transfer that privileges professional over lay knowledge (Lee & Garvin, 2003)

This study makes explicit the nature of knowledge exchange within SHE and makes recommendations for how this can be executed in practice.

Knowledge sharing

- Parents should be encouraged to share expertise through engaging in sleep assessment, interpretation and co-creation of customised SHE advice.

- Employing parent buddy and championing parent support groups

"It's very powerful to have er a parent as a buddy and as er I agree with you really it's more kind of moral support, cause I was there and I've been through it and you will get through it."

Practitioner

"We have spent a lifetime with these children and we are only just getting to grips with how they function so actually one-off sessions are a big 'no no' cause you don't get a true picture "

Parent

Health expectation

In addition to receiving customised, co-created advice, parents also need to feel hopeful child's sleep can improve.

It is posited if parents and practitioners maintain high expectations this will positively impact on implementation success

"A prediction about the consequences of certain health-related phenomena on the psychological condition of the body" Janzen et al (2005).

Health expectation

- Data shows how low health expectation impacts on sleep problem recognition.

- Practitioners sometimes have a negative outlook- discouraging parents at the start of their journey.

- Also parents coping regardless , belief sleep problems are inevitable and untreatable

- Data also indicated important to maintain parents hope during implementation.

- Practitioners need to adopt an enduring positive attitude.

"The way we work hopefully it allows parents to see that they can change."

Practitioner

"She did it very positive, it kept him hoping"

Parent

"I mean it took some convincing with my husband, you know that we had a problem in the first place because, in his generation in his parent's generation, it goes under the carpet you forget about it, it doesn't exist, well I'm sorry but it does."

Parent

Rationing & Gaming

"Hitting the target and missing the point" Bevan and Hood (2006).

The practice of organisations changing their behaviour when they know the results they report will be used to control them. (Nedwick, 2012)

It is posited that sleep teams reduce the accessibility of their service, to deter excessive referrals and keep waiting times within acceptable targets- to the detriment of families

Rationing & Gaming

- Data shows how teams provide limited geographical coverage and restrictive entry criteria.

- Practice of gatekeeping professionals which added another layer of complexity. Reflects another rationing and gaming strategy

- Wider implications added barriers for parents accessing support and delays to intervention.

- Such practises mask true level of service need.

- If magnitude of sleep problems is not visible through lengthy waiting lists the prospect of adequate provision remains improbable.

"Some families seem to fall through the net as well they don't fit this criteria."
Practitioner

"We're only working with children who have been referred and they are open to somebody else so it's the internal referrals and I'm sure there are lots of other children out there who are not open to our service
Practitioner

In conclusion

- This study aimed to develop a systematic understanding about what SHE does, how it is delivered and how it is supposed to work to improve sleep.

Overall findings were:

- An explicit understanding of the complexity embedded in an SHE intervention. Most importantly this study shows how the legitimation of sleep problems is a foundation on which SHE implementation should be based. Findings also demonstrate a greater understanding of the nature of customisation, health expectation, knowledge exchange and impact of rationing and gaming on implementation success.

Next steps

- Dissemination – Publications planned 2018.

- Theory driven framework for evaluating SHE

- Piloting and feasibility work is now required to ensure the intervention can be carried out as intended, before a main evaluative study can be designed.

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