Life Course Centre

WORKING PAPER SERIES

No. 2025-26

October 2025

A novel approach to tailoring a behavioural sleep intervention for children with neurodisability

Kasey Fullwood
Laetitia Coles
Karen Thorpe
Fiona Hudson
Karen Waters
Moya Vandeleur
Jasneek Chawla

The Australian Research Council Centre of Excellence for Children and Families over the Life Course
Phone +61 7 3346 7477 **Email** lcc@uq.edu.au
lifecoursecentre.org.au

Australian Government
Australian Research Council

The University Of Queensland
AUSTRALIA

The University of Sydney

The University of Western Australia

The University of Melbourne

Research Summary

Why was the research done?

Behavioural sleep disorders are common in children with neurodisability. Standard interventions require adaptations to facilitate effective delivery and child outcome. The aim of this study was to describe the process involved in the development of a tailored behavioural sleep intervention for the management of sleep disorders in children with neurodisability.

What were the key findings?

This paper describes a pilot study and methodological framework for a tailored behavioural sleep intervention for children with neurodisability who experience non-respiratory sleep disorders. Throughout the development process, a collaborative research approach was implemented, engaging family and child consumers, medical and allied health stakeholders. The consultations provided critical insights that enriched the intervention and delivered tailored strategies. The resulting intervention design was a two-session program: Sleep Foundations and Sleep Disorders and Strategies. The pilot data (n=8 families) identified strong satisfaction, and short-term outcome data (n=3) showed improved sleep quality and continuity.

What does this mean for policy and practice?

Use of a collaborative consumer focused methodology led to development of a tailored behavioural sleep intervention that is feasible and acceptable to families and children. Pilot data suggests potential for clinical use. Further efficacy trials are required to establish if the tailored intervention can optimise outcomes in children with neurodisability when compared to traditional interventions designed for typically developing children.

Citation

Fullwood, K., Coles, L., Thorpe, K., Hudson, F., Waters, K., Vandeleur, M., & Chawla, J. (2025). 'A novel approach to tailoring a behavioural sleep intervention for children with neurodisability', Life Course Centre Working Paper Series, 2025-26. Institute for Social Science Research, The University of Queensland.

The authors

Kasey Fullwood
Child Health Research Centre, The University of Queensland
Email: k.fullwood@uq.edu.au

Laetitia Coles
Child Health Research Centre, The University of Queensland
Queensland Brain Institute, The University of Queensland
Email: l.coles@uq.edu.au

Karen Thorpe
Queensland Brain Institute, The University of Queensland
Email: k.thorpe@uq.edu.au

Fiona Hudson
Child Health Research Centre, The University of Queensland
Departments of Respiratory and Sleep Medicine, Queensland Children's Hospital
Email: f.hudson@uq.edu.au

Karen Waters
Departments of Respiratory and Sleep Medicine, The Children's Hospital at Westmead
Child and Adolescent Health
Email: karen.waters@healthnsw.gov.au

Moya Vandeleur
Departments of Respiratory and Sleep Medicine, The Royal Children's Hospital
Murdoch Children's Research Institute
Email: moya.vandeleur@rch.org.au

Jasneek Chawla
Child Health Research Centre, The University of Queensland
Departments of Respiratory and Sleep Medicine, Queensland Children's Hospital
Email: jasneek.chawla@health.qld.gov.au

Acknowledgements/Funding Sources

The authors wish to acknowledge the consumers and stakeholders for their significant contribution to this research. This research was supported by the National Health and Medical Research Council, Australia through a Medicine Research Future Fund grant (Application ID 2018007).

We acknowledge the Traditional Custodians of the lands on which we work and live across Australia.
We pay our respects to Elders past and present and recognise their continued connections
to land, sea and community.

Abstract

Aim: Behavioural sleep disorders are common in children with neurodisability. Standard interventions require adaptations to facilitate effective delivery and child outcome. The aim of this study was to describe the process involved in the development of a tailored behavioural sleep intervention for the management of sleep disorders in children with ND.

Method: This paper describes a pilot study and methodological framework for a tailored behavioural sleep intervention for children with neurodisability who experience non-respiratory sleep disorders. Throughout the development process, a collaborative research approach was implemented, engaging family and child consumers, medical and allied health stakeholders. The consultations provided critical insights that enriched the intervention and delivered tailored strategies.

Results: The resulting intervention design was a two-session program: *Sleep Foundations* and *Sleep Disorders and Strategies*. The pilot data (n=8 families) identified strong satisfaction, and short-term outcome data (n=3) showed improved sleep quality and continuity.

Conclusions: Use of a collaborative consumer focused methodology led to development of a tailored behavioural sleep intervention that is feasible and acceptable to families and children. Pilot data suggests potential for clinical use. Further efficacy trials are required to establish if the tailored intervention can optimise outcomes in children with ND when compared to traditional interventions designed for typically developing children.

Introduction

Children with neurodisability (ND) are a group with acquired or congenital conditions caused by impairments of the brain and/or neuromuscular system that creates functional limitations [1]. Among children, severities and complexities of impairment are diverse and may result in difficulties with movement, cognition, hearing and vision, communication, emotion and behaviour [1]. Children with ND have nearly double the prevalence rates of sleep disorders when compared to typically developing (TD) children [2] and comprise both sleep disordered breathing (SDB) and behavioural sleep disorders. Common behavioural sleep disorders include sleep-onset delay, reduced sleep duration, frequent nocturnal awakenings and reported restless sleep [3]. In children with ND, sleep disorders are often complex, with features associated with their underlying condition often predisposing to behavioural sleep disorders [4]. Additional contributory factors include pain [5], hospitalisations [6], sensory and environmental sensitivities [7], a worsening of symptoms related to underlying comorbid diagnoses at night (such as nocturnal seizures) [8], intrinsic and extrinsic circadian rhythm disruptions [9, 10] and/or interactions of prescribed medications [11]. Such sleep disorders have an attendant impact upon the child's cognition, daytime behaviours, and growth, with associated effects on their health and wellbeing. Adverse effects also extend to the health and wellbeing of other family members. Treatment of behavioural sleep disorders typically include both pharmacological and behavioural interventions, which are often administered concurrently [12, 13]. Behavioural interventions have demonstrated efficacy in treating non-respiratory sleep disorders in TD children [14, 15] and specific sub-groups of ND [16-18]. However, the generalisability of these studies to the broader ND population is limited, highlighting the need for ongoing research [19].

A recent systematic review of behavioural sleep interventions to manage non-respiratory sleep disorders in children with ND, found that half of the included studies that demonstrated efficacy were adaptations of the format and content of interventions originally designed for use in TD children by employing tailored strategies (unpublished data). Adaptations primarily involved use of visual supports, including visual schedules and social stories [16, 20]. Modifications to language and content to address common behaviours, along with increased repetition in learning materials, were also employed [21]. Although these studies of tailored interventions demonstrated improvements in sleep for children with ND, many lacked detailed descriptions of the specific adaptations employed and the rationale for their use. Further, the degree to which families and children were consulted and involved in the development of such interventions was unclear. Incorporating child and family perspectives, alongside greater detail in the methodology of tailoring interventions, is essential to ensure appropriateness of intervention strategy in clinical practice. The use of inclusive, collaborative, co-design approaches are recognised as not only ethical but crucial for precision of intervention design when working with people with disability [22].

There is an increasing evidence base for the use of collaboration and co-design across a wide range of research settings, designing interventions *with*, rather than simply *for*, people with disability. Collaboration and co-design encourage deeper reflection, creativity, and incorporates the knowledge from those with diverse lived experience and expertise [22]. Actively involving consumers and providers ensures interventions are tailored to need and improves clinical practice, clinical outcomes, patient satisfaction and patient wellbeing [23].

Currently, there is no standardised approach for management of behavioural sleep disorders in children with ND with tailored approaches lacking and not commonly used. This paper

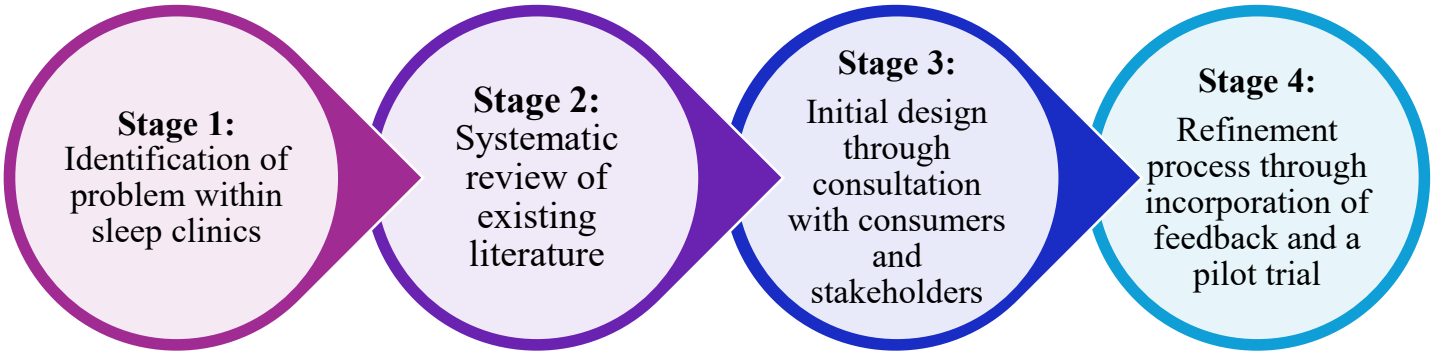
aims to describe the methodological framework employed to develop a tailored behavioural sleep intervention for children with ND, outlining the steps taken to ensure a comprehensive, consumer focused approach.

Method

The use of collaborative frameworks has a growing body of literature, and the authors acknowledge the variation in terminology used to describe varying degrees of consumer involvement [24]. For the purpose of this paper, the methodology reflects a collaborative research approach in which elements of co-design and co-production have been drawn on [25].

Figure 1 details the four stages of intervention development in the design of a behavioural sleep intervention for children with NDs. Prior to program development, a consumer advsiory group – comprised of primary caregivers of children with a ND receiving specialist sleep management within a tertiary sleep clinic – was established. Consumer advisors were identified by their primary sleep physician and invited to participate through direct contact from their primary sleep team at one of the participating three tertiary centres. All consumers were engaged in "Consumer Engagement Agreements" and were involved in the initial stages of the project development including scope of study and protocol finalisation for ethics. The consumer advisory team were reimbursed for their time and participation within consultations.

Figure 1: Stages of development for a behavioural sleep intervention for children with neurodisability.



Stage 1: Identification of knowledge gap

This research was conceptualised by sleep specialist clinician researchers in discussion with patients attending their tertiary sleep clinics. The consultation identified a lack of evidence-based resources to support management of children with ND presenting with behavioural sleep disorders. Families identified that the approach to management of their child's sleep disorders lacked structure and consistency, directing systematising delivery of supports a priority for improved care.

Stage 2: Systematic Review of Literature

A comprehensive review of existing literature was conducted to identify treatment approaches and modifications which have previously been undertaken to address the challenges experienced within sleep for children with ND (unpublished data). Among the studies reviewed, *Sleeping Sound* intervention [16] was identified as a high-quality study, which had undergone rigorous evaluation, with demonstrated efficacy for children with Autism Spectrum Disorder (ASD) and Attention-Deficit and Hyperactivity Disorder

(ADHD). Given the robust evidence for this program with a sub-group of children with ND, the *Sleeping Sound* framework was selected as the most appropriate base from which to develop our program, which focused on the needs of children with a broader group of ND conditions.

Stage 3: Initial Design

The initial intervention design presented the proposal of adaptations to *Sleeping Sound* to the consumer advisory group, who provided critical insights from the consumer perspective and highlighted additional considerations. Further, consumers provided perspectives on suitable format, length and mode of delivery of content. Notably, parents emphasised the importance of a parent-led intervention, directing a significant deviation from the original *Sleeping Sound* framework, which is directed towards the child.

Discussions were undertaken with the S*leeping Sound* development team [16, 26], who provided insights into their experiences from the original studies, including suggestions for changes to delivery method, potential adaptations to content and lessons learned from the challenges of implementation of S*leeping Sound*. Based on these insights, both a preliminary session format and prototype intervention were developed.

To gain further insights, the prototype intervention was reviewed by allied health professionals and medical specialists involved in the care of a child with a ND. Table 1 lists the health professionals who were consulted and a brief description of the topic of consultation. Each consultation began with the study team presenting an overview of the proposed intervention, including session structure, intervention content, an overview of accompanying resources (factsheets, worksheets, videos) and the planned strategies for managing sleep. Feedback was gathered and integrated, refining the program further with the

multidisciplinary insights significantly enhancing the proposed content. Examples of additional inclusions were incorporation of pain management techniques, impact of physical impairment and sleep positioning, strategies to address difficulties of key nighttime tasks (brushing teeth, dinner time, bath), sensory processing information and advice on medication administration. Full results of consultations and intervention changes can be found in Supplementary Table 1. The intervention was reviewed by members of the broader research team on structure, information delivery, visual design, and clarity of medical and psychoeducation content.

The next phase in the initial design involved the review of results of a cross-sectional survey involving 300 Australian families of children with ND (HREC/21/QCHQ/79027). This survey, undertaken as part of broader research on sleep in children with ND, provided information regarding the sleep priorities reported directly by parents for their child with ND. This consultation confirmed that the developed program aligned with parent priorities, most prominently, a focus on sleep onset association difficulties and night wakings for children with ND [27].

Table 1: *List of Key Stakeholder consultations and brief description of consultation topics*

Key Stakeholder	*Consultation Topic*
Speech Pathology	Communication Difficulties, Tools and Aids for communication
Physiotherapy	Pain, Sleep positioning
Occupational Therapy	Sensory profile of children, Impact of afternoon tasks on sleep
Sleep Specialised Nursing	Safety at night

Respiratory and Sleep Medicine Specialist	Medication administration, intrinsic circadian rhythm disorders, sleep disordered breathing
Broader Research Team	Structure and clarity of intervention delivery

Stage 4: Refinement Process

After incorporating consultation findings into the intervention program, a rigorous refinement process was undertaken to confirm that the interventions provided relevant, comprehensible advice and included appropriately tailored sleep strategies that addressed the varying needs of children with diverse underlying ND conditions.

The program was presented to a team of paediatric respiratory and sleep specialist physicians and nurses, the intended end-providers of the finalised program. Specialists provided specific feedback on the content, ensuring accuracy and clarity of medical advice and provided their views on the session format and the overall applicability of content to their patient population.

Primary caregivers of children with ND – the target recipients of the intervention program once integrated into clinical practice – were than consulted, applying two research methods:

(i) Consumer advisory meeting. Consumers were given access to previously recorded sessions facilitated by a researcher and the developed resources (List of resources developed in Supplementary Table 2). Consumers were consulted on their perspectives of the intervention sessions, identified areas requiring further refinement, highlighted underexplored treatment areas and provided feedback on clarity and understandability of the information.

(ii) Pilot trial. Eight families were engaged in a pilot trial once the changes suggested by the specialists and consumer advisory group were integrated into the intervention program. The primary goal of this pilot was to test the acceptability and feasibility of the refined program and identify any final adjustments required prior to efficacy testing.

4.1 Pilot Trial

Parents of children with ND were grouped according to the child's primary sleep problem as reported by parents (i.e., sleep onset problem, night-waking, restlessness or parasomnias) and developmental age group (preschool age, school age or high-school age), with 1-2 families in each group. Families completed the full telehealth intervention and provided feedback via semi-structured interviews and feedback form. Key feedback was sought on intervention design, flow of information, perceived relevance and value, inclusivity and the effectiveness of recommended strategies for their child. Additionally, participants completed the Child's Sleep Habits Questionnaire (CSHQ) before and immediately after the trial (4 weeks after baseline) to provide preliminary indication of any improvements in sleep as a result of the intervention program.

Results

Results reported comprise both the final design of the behavioural sleep intervention and outcomes of the pilot study.

1 Intervention design

The final intervention program consisted of two one-hour sessions, undertaken two weeks apart, with a follow up phone call two weeks after the final session. The final intervention format was by telehealth delivered to groups comprising 2-5 parents. Consumers advised that the intervention should be parent-led, with child participation an optional consideration for

parents. Additionally, they highlighted the importance of tailoring the program to developmental age due to differences in learning and relevant implementation strategies at different stages in development. As a result, the intervention was created with three age modules- a preschool age, primary school age and secondary school age module, with parents selecting the module they felt was most suitable for their child's developmental age. Specific findings and additions to intervention can be found in Supplementary Table 1.

1.1 Intervention Content

1.1.1 Session 1: Sleep Foundations

Sleep Foundations, explored psychoeducation of sleep, sleep hygiene and sleep routines. Full intervention content for Session 1 can be found in Supplementary Table 3. Adaptations for children with ND addressed key challenges and differences? within bedtime routines and sleep hygiene. Challenges included impact of daytime napping, rigidity in behaviours, difficulty maintaining routine and screen usage. While this information is also applicable for TD children, emphasis on differences experienced by children with ND was conveyed in the content. Examples of this included screen-time being beneficial for some children (e.g. to aid settling), some children requiring naps due to medical events (e.g. seizures or after rehab sessions) and some children having difficulty responding to changes in routines. Recommendations for communication tools included using social stories, visual schedules and reward systems to clearly communicate bedtime expectations and reinforce positive behaviours. Parents were encouraged to consider communication tools in the context of developmental age, with an emphasis on play based learning in younger children. A dedicated "Considerations Around Bedtime" section was incorporated to address specific concerns that may impact sleep. Examples of these can be found in Supplementary Table 3.

Group activities and discussions were facilitated to encourage families to reflect on their current bedtime routines and identify helpful adjustments based on the provided information. Facilitators guided parents in troubleshooting challenges and selecting appropriate communication tools. Parents were provided with a *Medical Carpark* resource, designed as a resource for addressing sleep related concerns that fell outside of the scope of the intervention. Examples of *Medical Carpark* topics included medical questions, medication prescribing or additional information on a treatment. Facilitators supported families in formulating specific questions for their healthcare team and identifying the most suitable healthcare professional involved in their child's care to whom these questions could be directed.

1.1.2 Session 2: Sleep Disorders and Strategies

Sleep Disorders and Strategies provided psychoeducation on specific sleep disorders and tailored evidence-based strategies. The consultation phase identified that the optimal method for delivery of intervention content was by grouping sleep disorders and the associated recommended treatments into four broad categories (Table 3). This approach was a deviation from the original *Sleeping Sound,* which focused on an individual sleep problem with specific strategies directed towards this problem only. Other adaptations from the original framework, informed by the consultation phase of our study, included use of gradual implementation methods, simpler, more concise resources comprising practical steps and modified measures of success.

Table 2. Sleep Disorder Grouping and subsequent management approaches

Sleep Disorder category	Specific Disorder	Specific Management Strategy
Sleep Initiation	Dependant sleep association Bedtime resistance Sleep Anxiety Delayed Sleep phased Racing thoughts Missed medication	Camping out Checking method Bedtime Pass Rewards Bedtime Fading CBT treatment Information to raise awareness of effect
Sleep Maintenance and frequent wakings	*Behavioural*: Sleep association Bedtime resistance Bedtime anxiety Early morning wakings *Medical*: Circadian rhythm disruptions Effects of medication Sleep disordered breathing Pain Sensory sensitivities. Environmental factors	*Behavioural*: Camping out Checking method Bedtime Pass Bedtime Fading CBT treatment Stay in bed method *Medical:* Education to make aware. Recommendations to address When to contact GP/ specialist Relaxation

		Sleep positioning Incorporating sensory activities or making aware of sensory disruptions
Restlessness	Pain Sleep positioning Sensory sensitivities Leg movements Seizures and body movements Restless sleep disorder Environmental factors	Education to make aware. Recommendations to address When to contact GP/ specialist Relaxation Sleep positioning Incorporating sensory activities or making aware of sensory disruptions
Parasomnias	Sleep terrors Sleepwalking Nightmares	Scheduled waking Safety Comfort Directing back to bed Dream imagery

1.1.3 Learning Frameworks

Extra scaffolding was included to assist with differences in learning and to facilitate successful implementation for families. The introduction of a "Step Ladder" framework focused on informing parents how to break down an overall sleep goal into small achievable

steps, using rewards to reinforce progress with each smaller step. Example “Step Ladders” were developed, and a section was included within session 2 where families would engage in an interactive activity, applying the Step Ladder framework to their own sleep-related goals.

1.1.4 Specific Sleep Content

As sleep related anxiety in the child was heavily reported by consumers, a specific module was developed to include a cognitive behavioural approach to sleep anxiety and night-time fears. Advice around the impact of medical events on sleep anxiety was additionally provided. Parents were again encouraged to use play and stories to convey concepts. Pairing anxiety strategies alongside the sleep strategy was encouraged for children who found change difficult or were experiencing distress at night-time. Additional details on the content of this module and specific sleep content within session 2 can be found in Supplementary Table 4.

1.1.5 Relapse Prevention

Our program included a relapse prevention element and provided information on sleep regressions. This was highlighted by both health professionals and consumers to be common in children with ND. Content included addressing the impact of hospital visits on sleep, developmental leaps, sickness and change in environment. Information was developed that could assist parents in predicting and preparing for a potential sleep regression, aiding them to recognise early cues and signs.

1.1.6 Communication Tools

Participants heavily relied on a diversity of communication tools, including social stories, to teach children new sleep skills and communicate expectations. Social story templates were created for each sleep strategy and provided to parents at the completion of the session, paired with advice to individualise stories, to engage specifically with their child’s needs and

situation. Additional resources included factsheets and videos, which were progressed from those developed by the *Sleeping Sound* team, tailoring to the study's population. These resources supported the information planned for each session and provided additional information on important topics related to sleep. A full list of resources provided to families can be found in Supplementary Table 2.

2 Pilot Study

Nine families participated in a pilot trial. Participants were children and families who engaged with a tertiary sleep clinic and were referred by their sleep physician to support management of a behavioural sleep problem. Groups were facilitated by two members of the research team and were run across a three-month period. Group were run for two sleep disorders prominent in children as identified by caregivers: sleep onset difficulties and night waking. Five groups involving 1-2 caregivers each, undertook the intervention. School aged and preschool aged sessions were run; high school aged participants were not recruited in this pilot group. Three participants completed pre-and-post measures, while all eight caregivers participated in a semi-structured interview.

2.1 Feasibility and Acceptability

Overall, caregivers rated the acceptability and feasibility of the intervention as high (N=3, 84.2%). Caregivers rated the level of support, technical ease, convenience of sessions and relevance of the information provided as the highest rated domains within the feedback questionnaire. Full findings can be found in Supplementary Table 5. All caregivers described the intervention as highly valuable, particularly appreciating the opportunity to connect with other families in the group. Strategies offered were described as tailored and relevant to children with ND. Some caregivers noted "It's not new information [intervention content] but presented in a new way that makes sense" and that "it felt reassuring we're doing the right

thing". Caregivers expressed that the sessions would be valuable to new families attending sleep clinics, providing consolidated sleep-related advice and management in one place, as opposed to engaging with multiple services. One caregiver mentioned "I wish I had this earlier as we would be further along". Many caregivers reported that the strategies were broadly applicable, useful for a child at any stage of learning and reported they had found it useful with other children within the household. Finally, caregivers consistently highlighted the benefit of the provided resources and tools, especially the "Medical Carpark" as extra support throughout the intervention.

2.2 Sleep Outcomes

Baseline CSHQ scores for participants (M= 60.7, SD= 8.5) reflected a clinically significant sleep problem (defined as scores >41) prior to the intervention. Total scores on the CSHQ showed improvement, with reduced scores observed 4 weeks after completing the intervention, compared to baseline scores (N=3, 10.8%). CHSQ subscales showed the greatest improvement in sleep onset delay (N=3, 22%), Sleep Disordered Breathing (N= 3,18.6%) Sleep duration (N=3, 14.8%), sleep anxiety (N=3, 13.9%) and bedtime resistance (N=3, 12.9%). All subscales within the CSHQ reflected clinical improvement in designated problems (Table 4), No caregiver identified parasomnia as their focus sleep problem, thus this intervention module was not delivered).

Table 3: Child Sleep Habits Questionnaire scores pre and post intervention and rate of change.

	P1 (pre)	P1 (post)	P2 (pre)	P2 (post)	P3 (pre)	P3 (post)	Overall change (N= 3)

Total Score	48	41	57	49	71	54	10.8% (10.67)
Bedtime Resistance	14	13	13	11	16	12	12.9% (2.33)
Sleep Onset Delay	2	1	2	2	3	2	22% (0.66)
Sleep Duration	3	3	7	6	9	6	14.8% (1.33)
Sleep Anxiety	8	8	8	5	6	8	13.9% (1.67)
Night Wakings	7	6	8	6	7	7	11.1% (1)
Parasomnias	8	7	10	10	11	12	0% (0)
Sleep Disordered Breathing	3	3	6	6	8	3	18.6% (1.67)
Daytime Sleepiness	9	6	6	6	18	13	11.1% (2.67)

*Percentage of change (point of change)

Discussion

This paper described the development of a behavioural sleep intervention for children with ND, employing a collaborative research framework to tailor the intervention to suit the specific needs of children. A small pilot study of families with preschool and primary school

aged children (n=8) assessed the program's feasibility and acceptability. Efficacy of the intervention was not the focus of the study and remains to be evaluated prior to clinical implementation. The development and trialling of the intervention presented key lessons for development of tailored interventions focused on co-design techniques and tailoring of programs.

Co-design: Working with consumers and stakeholders

Consumer advisory groups play a critical role in shaping effective interventions [28]. In the case of this study the consumer advisors shaped the intervention structure and focus, most notably influencing the decision to adopt a parent-focused rather than child-focused approach. Their involvement provided pivotal insights, identifying additional factors affecting their child's sleep, determining the balance between theoretical and practical content within the program and refining the program's duration, structure and visual presentation. Additionally, the expertise of the health professionals consulted assisted in integrating a range of treatment approaches, confirming accuracy of sleep education, directed troubleshooting topics and provided general advice around implementation strategies. Leveraging the expertise of both the consumer group and health professionals facilitated the development of an inclusive sleep intervention tailored to the individual needs of children with ND, rather than using a one-size-fits-all approach. The incorporation of scaffolding to adapt strategies based on individual needs ensured various sleep disorders across different ND groups could be addressed, making the intervention broadly applicable.

Previous consumer involvement reviews have highlighted the fragmented nature of consumer involvement in health research, citing inconsistent reporting and lack of authentic partnerships [29-31]. The methodology employed in this paper is unique within the sleep and

disability field. In research involving TD adolescents, Levenson and colleagues conducted focus groups with young adults, parents and health care providers to understand the key areas needed in a sleep intervention for adolescents [32]. Authors highlighted the critical role of key stakeholder contribution in developing interventions that are both acceptable and effective. While collaborative methodologies have been applied in various research fields, their use in the development of sleep interventions remain limited. In line with more recent literature [33-35], our findings demonstrate that a consumer-led approach was essential in shaping this intervention. This reinforces the growing consensus that meaningful and high-quality consumer involvement should be central to the design and implementation of health interventions to achieve optimal patient outcomes.

From our experience in this study, we propose a four-stage development approach (figure 2), incorporating elements of co-design and co-production to ensure a comprehensive and inclusive methodology. With collaborative research frameworks constantly evolving, the gold-standard approach has varied throughout the time of this project. As such, at the time of conception, co-design modelling was not available within the literature, thus has been incorporated as the field evolves. Figure 2 summarises the elements of the proposed collaborative framework.

Figure 2. Elements of a collaborative framework used through the four-stage development.

Project Development	Gaps	Intervention Development	Implementation
			
Consumer advisory group created Contractual agreements signed Consumer input into grant proposal and initial protocol	Consumer consultation on identified gaps	Consumer and stakeholder consultation to develop intervention. Intervention goals set by authors.	Implementation procedure guided by consumer and stakeholder feedback. Delivery conducted by authors
Co-design	Co-production	Co-production	Co-production

Elements of collaborative framework

Tailoring and Testing: interventions that work for children with Neurodisability

In interventions to support children with disability the need for tailoring to specific capabilities is required. In the case of developing this intervention key elements of adaptation were adaptations of content and delivery methods and provision of "Medical Carpark" for issues raised that sat outside the remit of the intervention. Beyond, an essential step in the development of the intervention was the assessment of its feasibility and acceptability prior to evaluating efficacy.

The pilot trial found the behavioural sleep intervention to be highly accepted and valued by caregivers. Improvements in child sleep were reported, including across various sleep behaviours. However, a high attrition rate was noted with minimal follow up data collected after the intervention concluded. This could be attributed to the timing of the follow up, which coincided with a busy time of year for caregivers, during the Christmas holiday season. Further, follow ups were requested and undertaken immediately after the intervention

concluded. The intervention is intensive in its implementation and therefore, caregivers may have had lowered capacity to complete additional questionnaires while implementing behaviour changes. Subsequently, the high attrition rate may introduce bias to the results with only those who perceived benefit completing the follow-up questionnaires. While the pilot trial yielded positive results, a small sample size limits these findings and further evaluation in a larger sample with longer follow up is required prior to clinical integration.

Within this trial, we included participants who were children under the care of a tertiary sleep clinic with respiratory sleep disorders being concurrently managed by respiratory and sleep specialists as required. Therefore, whilst it would be reasonable to attribute sleep improvements solely to the sleep intervention provided in our trial, it is important to acknowledge that additional treatment provided by the clinician as clinically indicated (eg, medication) could also contribute to positive results. This requires further evaluation within the setting of a randomised controlled efficacy trial.

Limitations of collaborative frameworks

Within child disability research, several barriers, including time constraints, heightened parental stress and reduced capacity for engagement can reduce the feasibility of fully immersive collaborative frameworks. While this framework enabled the development of an inclusive intervention, several challenges and limitations were encountered. One key challenge was the variability in consumer group engagement. Although all members initially participated in consultation sessions, engagement declined over time due to factors such as hospitalisation of their child with ND, illness and work commitments. Additionally, difficulties in scheduling, attendance and providing timely feedback posed further barriers to meaningful engagement. Another limitation relates to the potential biases in caregiver

representation. As consumers were caregivers engaged with a tertiary sleep clinic, participants may represent a subgroup of parents who are more actively involved in support networks and healthcare services, potentially excluding those with more limited access or capacity to engage. Moreover, not all ND subgroups were represented within the group, and thus may impact the generalisability of the intervention across broader ND populations. Despite the limitations discussed, this study presents the first sleep intervention program to have employed a collaborative methodological framework during development and is specifically tailored for children with ND.

Addressing Limitations

To address challenges in collaborative frameworks, flexibility in the way these are used in research may be necessary. Allowing caregivers to engage in varying capacities throughout the project lifetime may facilitate meaningful input, whilst minimising burden on those who have limited capacity to engage due to the caregiver burden they experience. Flexibility in levels of engagement for consumers and stakeholder throughout project timelines should be anticipated and planned for, with for example, the inclusion of a larger group of consumers, to account for periods of unexpected, unpreventable inactivity amongst individual members.

As the value of collaborative research is increasingly being recognised, exploration and documentation of the ways in which this methodology can be integrated into future intervention development would contribute to advancing methodologies within the field of sleep medicine and beyond. Currently, the intervention is being evaluated in a randomised controlled trial across three Australian tertiary hospitals (*HREC/2024/QCHQ/105383, ACTRN12624000736549*). This trial will determine its efficacy in treating behavioural sleep disorders in children with ND comparing to standard care. If found effective, this would be

among the first collaboratively designed behavioural sleep intervention to be clinically translated.

Conclusion

This paper demonstrates the benefits a collaborative research methodology to develop a behavioural sleep intervention for children with ND *with* families and end-users. Drawing on elements of co-design and co-production, the study highlights methods that can ensure the meaningful engagement of consumers and stakeholders to create a comprehensive and clinically relevant, applicable intervention which is now being evaluated in a randomised controlled trial setting.

References

1. Morris, C., et al., *Towards a definition of neurodisability: a Delphi survey.* Dev Med Child Neurol, 2013. **55**(12): p. 1103-8.
2. Aoife, M. and J. Desaline, *Paediatric neurodisability and sleep disorders: clinical pathways and management strategies.* BMJ Paediatrics Open, 2019. **3**(1): p. bmjpo-2018-000290.
3. Grigg-Damberger, M. and F. Ralls, *Treatment strategies for complex behavioral insomnia in children with neurodevelopmental disorders.* Curr Opin Pulm Med, 2013. **19**(6): p. 616-25.
4. Gilbertson, M., et al., *Determinants of sleep problems in children with intellectual disability.* J Sleep Res, 2021. **30**(5): p. e13361.
5. Valrie, C.R., et al., *A systematic review of sleep in pediatric pain populations.* J Dev Behav Pediatr, 2013. **34**(2): p. 120-8.
6. Hybschmann, J., et al., *Sleep in hospitalized children and adolescents: A scoping review.* Sleep Medicine Reviews, 2021. **59**: p. 101496.
7. Allen, K.D., et al., *Evaluation of a behavioral treatment package to reduce sleep problems in children with Angelman Syndrome.* Research in Developmental Disabilities, 2013. **34**(1): p. 676-686.
8. Al-Biltagi, M.A., *Childhood epilepsy and sleep.* World J Clin Pediatr, 2014. **3**(3): p. 45-53.
9. Jan, J.E., et al., *Neurophysiology of circadian rhythm sleep disorders of children with neurodevelopmental disabilities.* Eur J Paediatr Neurol, 2012. **16**(5): p. 403-12.
10. Zucconi, M. and O. Bruni, *Sleep disorders in children with neurologic diseases.* Seminars in Pediatric Neurology, 2001. **8**(4): p. 258-275.
11. Corkum, P., et al., *The Effects of Extended-Release Stimulant Medication on Sleep in Children with ADHD.* J Can Acad Child Adolesc Psychiatry, 2020. **29**(1): p. 33-43.
12. Angriman, M., et al., *Sleep in children with neurodevelopmental disabilities.* Neuropediatrics, 2015. **46**(3): p. 199-210.
13. Dorris, L., et al., *Sleep problems in children with neurological disorders.* Dev Neurorehabil, 2008. **11**(2): p. 95-114.
14. Blake, M.J., et al., *Systematic Review and Meta-analysis of Adolescent Cognitive–Behavioral Sleep Interventions.* Clin Child Fam Psychol Rev, 2017. **20**(3): p. 227-249.
15. Meltzer, L.J. and J.A. Mindell, *Systematic review and meta-analysis of behavioral interventions for pediatric insomnia.* J Pediatr Psychol, 2014. **39**(8): p. 932-948.
16. Papadopoulos, N., et al., *Sleeping Sound Autism Spectrum Disorder (ASD): a randomised controlled trial of a brief behavioural sleep intervention in primary school-aged autistic children.* J Child Psychol Psychiatry, 2022. **63**(11): p. 1423-1433.
17. Corkum, P., et al., *Better Nights/Better Days-Distance Intervention for Insomnia in School-Aged Children With/Without ADHD: A Randomized Controlled Trial.* J Pediatr Psychol, 2016. **41**(6): p. 701-13.
18. Bindels-de Heus, K., et al., *Sleep problems in children with Angelman Syndrome: The effect of a behavioral intervention program.* Res Dev Disabil, 2023. **135**: p. 104444.

19. Phillips, N.L., et al., *Behavioral interventions for sleep disturbances in children with neurological and neurodevelopmental disorders: a systematic review and meta-analysis of randomized controlled trials.* Sleep, 2020. **43**(9): p. 1-18.
20. Esbensen, A.J., et al., *Randomized Behavioral Sleep Clinical Trial to Improve Outcomes in Children With Down Syndrome.* Am J Intellect Dev Disabil, 2022. **127**(2): p. 149-164.
21. Georén, L., et al., *Internet-delivered Cognitive Behavioral Therapy for insomnia in youth with autism spectrum disorder: A pilot study.* Internet Interv, 2022. **29**: p. 100548-100548.
22. Fraser-Barbour, E., et al., *Shifting power to people with disability in co-designed research.* Disability & Society: p. 1-22.
23. Pearce, T., et al., *Co-creation of new knowledge: Good fortune or good management?* Research Involvement and Engagement, 2022. **8**(1): p. 65.
24. Vargas, C., et al., *Co-creation, co-design, co-production for public health – a perspective on definitions and distinctions.* Public Health Research & Practice, 2022. **32**(2 DOI - http://dx.doi.org/10.17061/phrp3222211): p. e2022.
25. Australasia, I. *IAP2 Public Participation Spectrum*. 2025 [cited 2025 August 6]; Available from: https://iap2.org.au/resources/spectrum/.
26. Hiscock, H., et al., *Impact of a behavioural sleep intervention on symptoms and sleep in children with attention deficit hyperactivity disorder, and parental mental health: randomised controlled trial.* Bmj, 2015. **350**: p. h68.
27. Langdon G, O'Neil M, Cooke E, Hudson F, Coles L, Vandeleur M, Waters K, Chawla J. Insights into the lives of families of children with neurodisabilities who have sleep problems. Sleep Health. 2025 Oct 4:S2352-7218(25)00177-9. doi: 10.1016/j.sleh.2025.08.007. Epub ahead of print. PMID: 41047332.
28. Green T, Bonner A, Teleni L*, et al*
Use and reporting of experience-based codesign studies in the healthcare setting: a systematic review
BMJ Quality & Safety 2020;**29:**64-76.
29. Constantin, N., et al., *The use of co-design in developing physical activity interventions for older adults: a scoping review.* BMC geriatrics, 2022. **22**(1): p. 647-10.
30. DelDot, M., et al., *Consumer Involvement in the Design and Development of Medication Safety Interventions or Services in Primary Care: A Scoping Review.* Health expectations : an international journal of public participation in health care and health policy, 2024. **27**(6): p. e70092-n/a.
31. Mathie, E., et al., *Consumer involvement in health research: a UK scoping and survey.* International journal of consumer studies, 2014. **38**(1): p. 35-44.
32. Levenson, J.C., et al., *Designing adolescent sleep interventions with stakeholder input.* Sleep Health, 2021. **7**(5): p. 581-587.
33. Schiffler, T., et al., *Characteristics and Effectiveness of Co-Designed Mental Health Interventions in Primary Care for People Experiencing Homelessness: A Systematic Review.* International Journal of Environmental Research and Public Health, 2023. **20**(1): p. 892.
34. Tu'akoi, S., et al., *The processes and impacts of co-designed health interventions by and for Pacific populations: a scoping review.* BMC public health, 2025. **25**(1): p. 2555.
35. Williamson, V., et al., *Restore and Rebuild (R&R) – a feasibility pilot study of a co-designed intervention for moral injury-related mental health difficulties.* European Journal of Psychotraumatology, 2023. **14**(2).