Project Title: Sleeping Better: Improving Sleep Habits in Children and Young People with Learning Disabilities using Cognitive and Behavioural Approaches

Keywords: Children with disabilities, sleep, behavioural approaches, melatonin

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Summary
The central childhood disabilities service in North Wales provides specialist assessment services for children/young people and their families. This service has two distinct elements: early years (0-5 years) and school age (5-18 years). Children are referred to the early years’ service for assessment, diagnosis and intervention that primarily focuses on supporting the child’s development in the areas of cognitive and social functioning. Referrals to the school age service generally request specialist assessment of the child/young person’s behaviour that is deemed complex and challenging.

Referrals for the assessment and management of sleep disorders make up a large proportion of referrals to both service elements. Initially children/young people are generally assessed by the community paediatric service and are, on the whole, prescribed sleep medication, namely melatonin, as a first line treatment approach prior to referral to specialist nursing provision. However there is existing evidence, that such difficulties can be effectively treated and managed using a range of behavioural and cognitive approaches (Durand, 2008; Vriend et al., 2011). This evidence prompted the project lead to hold discussions with the Clinical Director regarding how the Children & Young Person’s Clinical Programme Group (C&YP CPG) could explore sleep, its management and outcomes for children and families. These discussions resulted in an agreement to set up a work stream to develop a coherent strategy which would standardise treatment and focus on employing cognitive and behavioural management approaches as a first line intervention for both typically and non-typically developing children.

As part of this work stream, the project lead applied to the Foundation of Nursing Studies (FoNS) to support the service change required to enable staff to translate the new strategy into practice. The objectives of the project were to explore the impact of sleep loss/deprivation on families; ascertain clinical staff knowledge of sleep assessment/sleep management prior to developing a training plan and pilot a telephone help-line. The team used a mixed method approach including a training needs analysis using a staff survey (nursing and clinical psychology), which yielded a 69% response rate. This analysis provided a valuable insight into current knowledge and practice that clearly indicated staff training needs. This analysis enabled the work stream to explore and commission appropriate levels of training for different groups of staff. The training delivered by Sleep Scotland was
considered to be the most appropriate for the learning disability cohort due to the curriculum and teaching methods.

Five parent stories were collected and provided accounts of what it meant to live with a child who did not sleep well; these stories were analysed and three main themes emerged: ‘family impact, magnification and wishfulness’. The parent stories were used at training events and at work stream meetings to illustrate the impact poor sleep had on individual family members.

The project team asked the core nursing team to meet to discuss their claims, concerns and issues in relation to the project and proposed changes. This resulted in a change of direction for the project from the development of a telephone help-line to the establishment of a C&YP CPG wide childhood disability nurse led sleep clinic. The sleep clinics, whilst in their early stages of development have been operating weekly in ‘Central’ since September 2014. Parents are referred to the clinic and opt-in to a choice appointment once they have received a confirmation letter.

Lastly, the project team developed a sleep management information leaflet and booklet for families; they sought feedback from a range of sources: parents, clinical practitioners and the third sector. The feedback prompted significant changes to the language used and layout of the booklet before being submitted to the local health board for final approval. This is now being used at the nurse led sleep clinics.

Background
The Childhood Disability Community Services currently sits within the Children and Young Persons Clinical Programme Group (C&YP CPG); it is accountable to the Children’s Service Board (CSB), which in turn is accountable to the Betsi Cadwaladr University Health Board (BCUHB). The C&YP CPG spans six local authorities and is configured into three broad localities: West, Central and East.

The Childhood Disabilities Service is a stand-alone specialism that is made up of core staff from nursing, clinical psychology, speech and language therapy, consultant psychiatry and paediatrics. Teams are relatively small across each area and average 20 core professionals with the nursing team making up the critical mass. Services are provided from dedicated children centres across these localities. Referral criteria and service specification differ slightly in each area; this is historical and was a by-product of merging three health boards into one. It is anticipated that the imminent organisational structural change will engender consistent service provision across North Wales.

In Central there are two dedicated centres that accommodate core staff, with both functioning as integrated trans-disciplinary health teams. Both centres deliver a cohesive service in the assessment and treatment of children and their families. The service is currently configured as two distinct elements: an early years’ service (0-5 years of age) and a school-age service (6-18 years of age). Approximately 43 pre-school children each year are referred by primary health services to the early years’ service for the assessment, diagnosis and delivery of therapeutic interventions that focus on supporting the child in their cognitive, language, social, play and physical development. The school age service receives on average 80 referrals per year for specialist assessment and intervention. School-age children have to meet a specific eligibility criteria where they have a recognised learning disability (IQ <70 with concurrent deficits in adaptive functioning) and are engaging in behaviours deemed complex and challenging. Referrals to this service are generally received from secondary health service staff, social services or education departments.

The nursing team are fully involved in the assessment of the child’s cognitive/social needs; this may involve providing support at the children’s centre, at out-patient clinics or within the family home. This work includes offering specialist support in encouraging the child’s development in the areas of
play, communication, behaviour and social functioning. Further to this, the nursing team also engage in the functional assessment of the child/young person’s behaviours that at times can be complex and extremely challenging; with sleep problems being a significant challenge.

Children and young people with additional learning and support needs are reported to experience more serious sleep problems than typically developing children (Didden and Sigafoos, 2002). They may find it hard to settle, or wake and be disruptive in the night, or wake very early in the morning. As a consequence parents and other family members experience disrupted sleep patterns that can affect their own well-being; this can lead to higher levels of stress and for some family break-up (Allik et al., 2006; Jan et al., 2008).

It was the pioneering work conducted by Durand (2008) that sparked an interest within the Central nursing disabilities team to develop a local clinical pathway (Catherall and Williams-Jones, 2011) with a view to challenging how they assess and manage sleep difficulties. Management of sleep difficulties for this cohort of children and typically developing children within BCUHB relies heavily on prescribed medication; this is in spite of the empirical knowledge that such difficulties can be effectively treated and managed using a range of behavioural and cognitive approaches (Durand, 2008; Vriend et al., 2011). In addition to this, a recent study questioned the efficacy of melatonin in the treatment of sleep settling and sleep disturbance (Appleton and Gringras, 2011). This prompted the project lead to call a meeting with the Clinical Director of the Children’s Service Board to discuss how sleep difficulties are managed across the C&YP CPG.

A focused sleep management work stream was established as a result of these discussions. The purpose of the work stream was to establish a task and finish group with a remit to review current service provision for sleep management and to steer the development of an equitable, evidence based sleep management service across North Wales. The task and finish group consisted of a range of clinical practitioners that included consultant psychiatrists, consultant paediatricians, clinical psychology, nursing, medicine management and finance. The group met on 5 separate occasions that spanned the period from January 2013 to July 2013 and then again in November 2014 to review progress.

The group agreed and worked towards 7 actions that were endorsed by the Children’s Service and C&YP CPG boards; these were to:

- Undertake a formal clinical review of children who are prescribed medication
- Develop a sleep management pathway in accordance with the model developed by Catherall & Williams-Jones (2011) (see Appendix 1)
- Develop a training/awareness strategy ‘Sleep is everybody’s business’
- Invest in the training of clinicians in behavioural and cognitive approaches
- Invest in sleep support workers who would be able to provide direct support in assisting parents to establish good sleep hygiene and to maintain them
- Agree a prescribing model for melatonin
- Develop a financial plan to support the pathway and service provision and identify the savings to be gained

In tandem with the work stream development, the project lead expressed an interest in developing a dedicated telephone helpline with resources; this prompted and resulted in a successful application to the Foundation of Nursing Studies (FoNS). The project team consisted of three members, two clinical specialists, one with a background in clinical research and service management, the other an experienced paediatric trained nurse, the third an experienced healthcare support worker. The
project team considered it important to have staff that are operating at various levels within the organisation.

**Aim and objectives of the project**
The principal aim of the project was to enable the specialist nursing staff to take a consistent approach to the assessment of children with sleep disorders. This would include the use of a behavioural management approach to these problems, as a first line approach, with a view to reducing the use of prescribed medication.

This aim complemented the C&YP CPG's strategy to improve the outcomes for children and their families, and to enable all practitioners to follow a clinical pathway that focuses on collating sleep history with a two-week sleep diary prior to developing a behavioural intervention plan, as first line intervention.

To support this aim, the following objectives were developed:
- To understand the training needs of staff in relation to sleep disorders
- To understand the carer and family perspective of living with a child with a sleep disorder by collecting parent stories
- To engage and work with the core nursing team to implement possible treatment options into practice. Initially this had included the establishment of a telephone help line. However, as will be seen below, this was later changed to the establishment of a nurse-led sleep clinic
- To develop ‘sleep’ literature for both parents/carers and clinicians and to get feedback on it

**Methods and approaches**
The project team used a mixed methods approach. For the purpose of this report each approach will be discussed individually as a phase. Table 1 illustrates the time line of these phases.

**Table 1: Phases of the project**

<table>
<thead>
<tr>
<th>Phase</th>
<th>Approaches</th>
<th>Expected Outcomes</th>
<th>Date</th>
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<tbody>
<tr>
<td>Phase one</td>
<td>To develop and conduct a staff training needs analysis</td>
<td>To gain an understanding of trans-disciplinary knowledge and skills in the assessment and management of sleep problems. This information will then be used to inform future training requirements.</td>
<td>March 2013</td>
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<tr>
<td>Phase two</td>
<td>To collect and analyse parent stories</td>
<td>To provide evidence that clearly captures parent accounts of their personal experiences.</td>
<td>July 2013</td>
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<tr>
<td>Phase three</td>
<td>To work with the core nursing team using a Claims, Concerns and Issues exercise</td>
<td>To give the core nursing team an opportunity to contribute to and strengthen their involvement in the project.</td>
<td>October 2013</td>
</tr>
<tr>
<td>Phase four</td>
<td>To develop literature and obtain parent and professional feedback on developed literature</td>
<td>To provide internal and external validation of the developed literature.</td>
<td>September to December 2013</td>
</tr>
<tr>
<td>Phase five</td>
<td>To implement treatment options into practice</td>
<td>Explore and work with nursing staff to set up sleep clinics</td>
<td>February 2014</td>
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</table>
Training needs analysis

Conducting a training needs analysis can be defined as the initial step in a cyclical process that contributes to the overall training and educational strategy of staff in an organisation or a professional group. The cycle commences with a systematic consultation to identify the learning needs of the population considered, followed by course planning, delivery and evaluation (Gould et al., 2004). In order for any training needs analysis to be effective it must be carefully planned and have clear outcomes to ensure that training interventions are implemented effectively and that they lead to meaningful change in service delivery (Pedder, 1998).

The training needs analysis was conducted in the form of a staff survey (see Appendix 2) and was designed so that staff could self-report on their knowledge or lack of knowledge relating to: typical sleep patterns and sleep disorders; collecting and analysing sleep data and the use/awareness of cognitive/behavioural approaches to manage sleep problems. This approach is reported to have limitations, most significant, the possibility of receiving superficial data (Coolican, 1999). In spite of this and other limitations, this method was chosen by the project lead, as it would provide a snapshot and capture information from clinicians who already support and manage sleep as part of their core work. Further to this, the aim of the training needs analysis was to identify the skills and knowledge the Children’s Learning Disability Team practitioners already possessed as well as identifying any gaps that existed. Any identified gaps would formulate the service training needs. The questionnaire was sent electronically to all nursing and clinical psychology practitioners within the Children’s Learning Disability Teams across BCUHB. Forty-eight questionnaires were sent out and 33 were returned, yielding a 69% response rate. The training needs questionnaire was analysed by the project lead using simple percentage statistics and content analysis from the comments. This analysis guided the training needs of all practitioners.

Training needs analysis outcome

The outcome of the training needs analysis demonstrated that there were differences in approach across the health board in relation to how practitioners assessed and treated sleep problems. Most respondents (75%) reported that they understood typical sleep cycles and disorders and used sleep diaries as standard practice, of these 57% only used sleep hygiene assessments alone, and 30% used a standardised sleep habit questionnaire. It is of note to highlight that 52% of the staff used a sleep behavioural log, however only 30% of practitioners analysed and plotted data from these logs.

Staff knowledge relating to behavioural approaches in the management of a sleep disorder illuminated inconsistencies in current practice. For example, 60% of respondents reported an understanding of how to implement extinction based programmes, though 40% of them were unable to distinguish between a graduated and non-graduated approach. Thirty six per cent of practitioners were familiar with and used faded bedtime (with or without response cost), whilst 48% of them utilised stimulus fading where appropriate. Given the widely known work of Durand et al. (Durand, 2002; Durand and Christodulu, 2004) it is alarming to report that 82% and 64% respectively were unfamiliar with behavioural management approaches such as sleep restriction and scheduled awakening. Further to this, none of the respondents were familiar with chronotherapy (see Appendix 3 for explanation of the behavioural terms).

Having highlighted these differences in approaches, the project team produced a training session in the form of an interactive presentation. The presentation focused on typical sleep requirements across the child age range, the purpose of keeping and analysing sleep data and the behavioural approaches that could be employed to manage sleep settling or sleep disturbances. This presentation was piloted by delivering it to the West’s child disability nursing team. Fourteen staff attended the training afternoon, they engaged in the interactive process and had the opportunity to analyse ‘real life’ sleep diaries and identify appropriate interventions ‘in action’.
The training was evaluated by means of a questionnaire completed by the staff who undertook the training session; the evaluations demonstrated that the training proved to be very effective and useful for the practitioners who participated. As a result of the training sessions staff felt more confident in how they assessed and offered sleep advice.

One of the key tasks of the work stream was to locate and commission appropriate training, a task which took an extended length of time. For the child learning disability cohort, Sleep Scotland were contracted to provide this training. Thirteen nurses who had expressed an interest in developing their skills in this area were identified from across the localities. Sleep Scotland provided 5 days’ intensive training over a 3-week period split into 3 and 2 days respectively in May 2014. The first week focussed on known sleep science for typically and non-typically developing children, the impact on learning and well-being for the child and for those in a caring role. The second week enabled delegates to develop familiarity and confidence in conducting a sleep history assessment prior to the interpretation of sleep diary information and the development of a treatment plan. The training was conducted via plenary sessions and small group role play.

As part of the commissioned training, a follow up half day was held in July 2014. This enabled practitioners to present and discuss cases with a view to developing sleep counselling competencies.

**Parent stories**

The second phase of the project involved obtaining personal stories from parents of children who were known to have long term sleep problems. Parents who attended the children’s centre were asked if they would be willing to write a personal account of their experience. Five parents volunteered and met individually with two members of the project team. The purpose of these meetings was twofold: firstly to discuss the content and style of the account, and secondly, to obtain verbal consent for their personal story to be shared as part of the project. After obtaining consent, each parent was asked to provide their account using a medium of their choice, be it a written story, prose or any other art form. All five parents chose to provide a written account of their personal experience of what sleep meant to them within the context of family functioning.

Personal stories can effectively place the experience of families in need of services at the core of that service; they provide valid and important evidence for clinical decision making (Koch, 1998) as well as driving changes within public services.

To enable the thematic development of the parent accounts a computer software package (NUD*IST Nvivo, 2000) was used to assist in the clerical and data management task of moderating sets of raw data. This computer software package enabled the indexing, coding, searching and retrieval of this data prior to the development of key and sub themes. It is these themes that collectively illustrate the essence of what it means to live with sleep deprivation within the family.

**Parent stories outcomes**

The personal stories proved very powerful in driving the project forward particularly in influencing engagement from the work stream members. Extracts from the personal stories were presented to the work stream members which highlighted the impact chronic sleep deprivation had on the whole family. One particular quote taken directly from a personal story was used as it simply captured and conveyed the essence of living with a child who has enduring and chronic sleep problems.

‘The subject of sleep is something I have talked about, obsessed about, dreamt about, worried about and thought about continually for 2 years. It has taken over my life.’
Such personal stories brought the problem to life and highlighted the reality of caring for a disabled child as well as being sleep deprived. This and other extracts were also used when delivering in-house training to nursing colleagues, these extracts again highlighted and contextualised the day to day challenges faced by parents.

The project team analysed the personal stories, as described above and found the data identified three main themes: ‘family impact, magnification and wishfulness’; these themes were further divided into sub themes

Family Impact

The first main theme was ‘family impact’. Research demonstrates that having a child with a chronic sleep problem can have a detrimental effect on both the child and family (Polimeni et al., 2007) with the child’s sleep problems often only coming to the attention of practitioners because of the impact sleep deprivation is having on the parents. Crowe et al. (1996) identified that poor sleep results in high levels of stress, which in itself contributes to disorganised sleep patterns (Bates et al., 2002). France and Blampied (1999) describe this process as a ‘behaviour trap’ in which both parent and child behaviours interact and the sleep problem is maintained. This ‘behaviour trap’ was referred to within a personal story as ‘a vicious cycle with huge knock on effects’.

Emerging sub-themes from the ‘family impact’ theme included ‘relationship difficulties’, primarily between siblings, spouses as well as extended family and friends. One story read:

‘When your child doesn’t sleep, the whole family dynamics are affected. The pressure it puts on your marriage and friendships is very testing.’

One parent reported practicalities affecting the siblings such as:

‘Some days I have missed taking my little girl to school as I have not felt safe enough to drive.’

With another reporting how her other child’s school work was suffering:

‘... as he can’t concentrate and has been known to be fractious with his friends ... he also becomes clumsier, short tempered, tearful, angry and argumentative...’

Another parent reported:

‘... as a couple, we don’t get to go out and socialise as I feel I can’t leave him with anyone else as it’s not fair on them.’

Another emerging sub theme identified was parent reports of a reduction in their ‘ability to function’, both physically and mentally:

‘... mentally drained, exhausted and feel like you are losing your mind and on the brink on a nervous breakdown.’

Another parent reported physical disturbances from excessive tiredness:

‘... the abdominal pain, the nausea, the vomiting also experienced at intervals during the night when your little boy is awake, you have to push to one side.’
Magnification
A second main theme identified from the data analysis was ‘magnification’ of the reality of day-to-day living. One parent reported:

‘Everything seems a hundred times worse ... I’m so tired and feel like I’m running on empty ... people are treading on eggshells around me.’

Whilst two parents reported:

‘becoming overwhelmed and seeing the worst in everyone and everything.’

‘Everything can be such an effort ... bedtime is a million miles away and you don’t know how you’re going to get through the day.’

Another mother stated:

‘Physically you don’t even recognise yourself in the mirror ... It’s very easy to forget the person you used to be.’

As well as a sense of magnification, parents also commented on their overwhelming feelings of ‘guilt’. ‘Being self-obsessed with sleep’ and ‘for feeling this way...’ that they experienced feelings of guilt for thinking and behaving as they were.

Wishfulness
The third and final theme identified was that of ‘wishfulness’; a wishfulness to be ‘normal’, with a desire to simply be able to sleep!

One parent described the state of hope and optimism that they feel after a chance night of uninterrupted sleep but are shattered when it is short lived:

‘When those infrequent full night’s sleep happen, you are so grateful and wonder if this is the start of things to come but then are highly disappointed when you return to broken night’s sleep the following night.’

The personal stories demonstrated to the project team as well as the identified stakeholders, namely the work stream and nursing teams, how difficult day-to-day life can be for families living with a child with sleep problems. The project lead presented the themes from the parent accounts to the work stream members with a view to illuminating the lived experience of the parents. The impact of this observed by the project lead, was that some were taken aback by the emotional content/rawness/power of the statements and looked visibly shocked by the impact the lack of sleep was having on the lives of parents and other family members.

Engaging the core nursing team
The core nursing team had been identified by the project team as being in the best position to implement the changes in sleep management into practice. Within practice development this group of staff could be identified as the ‘critical community’ (Titchen and Manley, 2007) who would be key in furthering the project’s aims.

The project team invited the core nursing team to meet them to discuss how the project was progressing and to start to explore how to implement treatment options into practice. At the start of the meeting the project team gave a short presentation in relation to what had been achieved so far
and then the project lead invited the team to take part in a claims, concerns and issues (CCI) exercise derived from fourth generation evaluation (Guba and Lincoln, 1989). This exercise is often used to gain the engagement and participation of stakeholders. Each member of the team was asked to write down and share the positive aspects of the project (Claims) and then any concerns they had relating to the project (Concerns). The concerns were then turned into questions (Issues) and team members were invited to seek solutions for these questions.

The CCI exercise was facilitated by the project team, who met on two occasions to plan the format of the session; this included developing the presentation and agreeing who would do what. The CCI exercise was conducted at one of the Central nursing team’s routine monthly meetings. Twelve members of staff attended the meeting at the children’s centre. The project lead set the scene by delivering a presentation that detailed the aims of the sleep project before explaining the CCI exercise. The 2 other members of the project team engaged in facilitating and recording discussions. The project lead closed the meeting by summarising the project aims and salient concerns and issues raised.

All expressed concerns were reframed into questions (issues) (see Table 2). Once the issues (or questions) had been listed, the Central nursing team spent some time considering them. It became clear that some were easier to explore and answer than others; time management and staff training were easier problems than more abstract issues such as managing parental expectations and working with hard to reach families. The project team agreed to further deliberate on these more difficult questions and offer further consultation and discussion at future nursing team meetings.

Conducting the CCI highlighted the complexity of facilitating a change process that required the engagement of all nursing staff in order for the change to happen effectively.

**Table 2: Claims, Concerns and Issues**

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<thead>
<tr>
<th>Claims</th>
<th>Concerns</th>
<th>Issues</th>
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<tr>
<td>• Behavioural methods are more sustainable in assessing and managing sleep if adopted as an early intervention</td>
<td>• Time</td>
<td>• Is there a danger of being overrun with sleep problems?</td>
</tr>
<tr>
<td>• Use of medication as a first line approach is costly in terms of financial governance and cost to family</td>
<td>• Parents understanding</td>
<td>• How many hours will the telephone helpline be open?</td>
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<tr>
<td>• C&amp;YP CPG board have agreed the work stream to reduce expenditure, look at staff training needs and adopt cognitive/behavioural methods as first line assessment/treatment with an expectation that all practitioners will fulfil this task within their current role</td>
<td>• Parent literacy skills</td>
<td>• Who follows up?</td>
</tr>
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<td></td>
<td>• Parents willingness to become involved</td>
<td>• Is there a script?</td>
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<td></td>
<td>• Parental expectation</td>
<td>• What about other disciplines?</td>
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<td></td>
<td>• Parental exhaustion</td>
<td>• Will it involve shift and night working?</td>
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<td></td>
<td>• Support for staff</td>
<td>• How will we manage hard to reach families?</td>
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<tr>
<td></td>
<td>• Supervision</td>
<td>• Are we totally ruling out prescribed medication?</td>
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<td></td>
<td>• Resources</td>
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<td></td>
<td>• Staff competency</td>
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<td></td>
<td>• Follow up for families</td>
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Claims, concerns and issues exercise outcomes
All of the 12 staff participated fully in this exercise. The Claims, Concerns and Issues exercise provided a framework that enabled staff to think about and explore aspects of the project in a way that was not familiar to them. Nonetheless, they were able to raise and explore a range of concerns and issues. In essence this exercise highlighted a consensus of opinion and an acceptance that current practice was failing to meet the presenting needs and that as nurse practitioners it was possible to deliver services in a coherent and evidenced way. Further to this it stimulated the project team’s thinking and raised questions as to how the project would proceed in the future.

Production of leaflet and booklet and feedback
The fourth stage of the project comprised of 2 parts

- Developing ‘sleep’ literature for both parents/carers and clinicians
- Gaining feedback from stakeholders including parents/carers, professionals and specialist sleep practitioners

Two members of the project team were tasked with developing the sleep literature: a leaflet and a booklet. It was intended that the leaflet would have a health promotion focus and would be provided for parents and carers of young children. The aim of the leaflet was to promote healthy sleep habits that encourage the development of bedtime routines from an early age and would be in accord with World Health Organisation (2014) healthy lifestyle principles. The booklet would offer specific advice for parents, carers and professionals supporting children and young people with additional needs. The aim of the booklet was to provide the reader with empirical sleep information that would enable them to make positive changes to improve their child’s sleep. The booklet would also contain details for further advice/support via the proposed telephone helpline.

The project team members met on eight occasions to generate ideas regarding the development of appropriate and evidence-based sleep information as well as ensuring that the leaflets met with trust guidelines on producing ‘patient information leaflets’. Gathering evidence-based sleep information involved conducting an online rapid literature search of current research. The project team then utilised a desktop publishing facility to design the layout of the leaflet and the booklet.

As well as ensuring compliance with the trust guidelines, the project team were guided by ‘Niace’ (2009) readability principles. These principles guided the project team in presenting the leaflet and booklet clearly, whilst taking into account the needs of the readers. This involved careful consideration of the design and readability that was in line with the Simple Measure of Gobbledygook (SMOG) test (Niace, 2009). Once the project team were satisfied with the layout and content of both products they were professionally proof read and printed before seeking feedback from stakeholders.

Freeman (1985) suggested that feedback has an important role in all change processes. Indeed, feedback can facilitate or hinder change by ‘identifying’, ‘clarifying’ and ‘evaluating’ barriers to achieving change. Compton and Gallaway (1979) suggest that the act of seeking feedback keeps the change process ‘dynamic, relevant and mutual’.

To this end, the project team produced a feedback questionnaire (see Appendix 4), which was given to parents, professionals and appropriate representatives from the third sector.

Feedback outcomes
The feedback received from professionals and parents was very positive particularly in relation to the sleep hygiene leaflet. The sleep management booklet received more critical review with
comments such as ‘too wordy’, ‘overly complicated’ and ‘some of the routines sound complex and not easy to understand or follow’.

The most significant critical feedback relating to the booklet was received from a specialist sleep practitioner who worked in the third sector. This feedback prompted the project team to reflect and reappraise the layout and content of the booklet. The language used was simplified, medical and technical jargon was removed entirely and a sleep diary was inserted with the intention that it could be completed by parents/carers prior to attending a sleep clinic.

Following this revision, the leaflet and booklet have been professionally proof printed (see Appendix 5) and have been approved by the Health Board’s Patients Experience Committee; the leaflets are awaiting translation into Welsh and other languages as per the Health Board’s policy.

**Implementing treatment options into practice**

The objective to develop and pilot a sleep telephone helpline originated from the project lead. The idea of a helpline was chosen because there were limited resources, which would impact on the service’s ability to meet current demand. The original concept of developing the helpline grew in stature following ‘in principle’ work stream support. However, as the project developed, a change in direction was indicated. Two main factors contributed to this, namely the outcomes of the CCI exercise and the Sleep Scotland training.

Whilst there was support in principle for the project’s objectives, the nursing team were empowered via the CCI exercise to explore and raise any concerns they held. It became apparent that the nursing team were concerned about their current capacity and were already struggling with the demand, so didn’t feel they would be able to ‘man’ a telephone helpline. It also became clear, following the Sleep Scotland training, that the idea of establishing a dedicated nurse led sleep clinic across C&YP CPG, rather than continuing with the development of dedicated telephone helpline as first envisioned, may offer a better alternative to meeting the broader sleep work stream’s objectives.

To develop this idea further the project lead organised a meeting in conjunction with the child disability service manager, with 13 nursing staff who had completed the Sleep Scotland training. The purpose of this meeting was to discuss the practicalities of implementing nurse led sleep clinics across C&YP CPG. It was agreed to run weekly nurse led clinics across North Wales, with Central service commencing September 2014. Appendix 6 details the agreed nurse led sleep clinic pathway that incorporates the main tenets of the original sleep management pathway (see Appendix 1).

The East and West service commenced running nurse led clinics in November and December 2014 respectively. Clinics are held weekly either at the children’s centres or other locations that meet family needs. Families who are referred, are contacted by letter explaining the purpose of the clinic and are given contact details to arrange an appointment. To date the central clinic has been experiencing a 50% ‘Did Not Attend’ (DNA) rate. It is thought that the reason for this is that some families are receiving a prescription of melatonin prior to their referral, therefore negating their need to attend clinic. This issue has been raised and discussed at the work stream meetings with an outcome that prescribers will be asked not to prescribe melatonin prior to making a sleep clinic referral. In practice this has resulted in a marked reduction in DNAs, now at 20%. Some parents continue to be prescribed melatonin prior to and following clinic referral. In these instances the prescription for a maximum of two-months (with review) is being used flexibly as part of an integrated sleep management programme.
Early evaluation data collected so far indicates that 13 of the 24 parents who have been referred to the Central clinic have opted in and attended. Of these, 7 mothers have reported an improvement in their child’s sleep onset/latency.

The general impression of the project lead is that referral rates have exceeded expectations and the clinic has now received 24 referrals since September. The new pathway and sleep clinic enables nursing staff to meet families’ needs specifically in relation to sleep issues, which was previously not possible as staff were drawn in to other family issues such as housing, finances (benefits) and education/other support services. To support the nursing staff with the sleep clinics the project lead has also organised a monthly case-discussion meeting which allows time to plan and discuss cases and ‘gives’ permission to focus purely on sleep.

Discussion
The aim of the project was to ensure that nursing staff took a consistent approach to the assessment of children with sleep disorders and that they adopted a behavioural management approach to these problems with a view to reducing the use of prescribed medication, whilst improving outcomes for children and their families. The project team consisted of three members, who all worked within the same team but with different levels of responsibility. The very nature of the skill mix: service manager, community sister and healthcare support worker could have created an autocratic dynamic with the service manager directing the pace, direction and task allocation of the project. In practice, the project team worked collaboratively, instinctively and enthusiastically in meeting and furthering the project aims. It was the individual characteristics of each team member that enabled the project to develop and move forward in a cohesive and mutual way during the phases of planning, implementation and evaluation. Whilst there was healthy discussion and on rare occasions disagreement, the project team worked productively during the course of the project term, the development of the literature is testament to this. Outside the direct project team, the wider nursing, psychology and medical team have been highly supportive of the project’s aims and direction by providing positive feedback and offering encouragement.

The practice development workshops facilitated by FoNS were also instrumental in enabling project team members’ growth in confidence. This has been particularly true in their increased confidence in presenting change ideas to the immediate and wider team. Exercises such as claims, concerns and issues are immensely useful and are viewed by the project team as exercises that will be used again during service development days. The use of personal stories has brought richness and additional meaning, so much so that they have impacted on staff views and attitudes, thus contributing in driving the project aim.

One of the original objectives of the project was to establish and pilot a telephone help-line. This concept had been firmly embedded in service thinking for some time prior to and during the early and middle phases of this project. Two significant and key moments during the latter phases namely conducting the claims, concerns and issues exercise and the content of the sleep counsellor training, influenced the project team’s thinking and its overall direction. It was clear from the claims, concerns and issues exercise that the nursing team accepted that, for them to meet service demands, they would have to practice differently. But it was also clear that without additional resources they would struggle to take on additional responsibilities: a dichotomy. The training programme delivered by Sleep Scotland likewise offered the project team alternative ways of delivering a sleep service: establishing small dedicated teams across each area. This model of service delivery in essence would enable the wider team to refer all sleep related issues to the clinics; thus ‘freeing’ them to concentrate on other issues of practice, for example significant behavioural challenges. These two factors were the catalyst for changing the project team’s direction to the establishment of a nurse led sleep clinic service across North Wales.
The project team experienced difficulties in keeping to deadlines. These were attributed to delays in the commissioning of the new children’s centre and time management issues. The team reflected on the latter and considered how they would be managed if starting afresh. One of the key presenting issues was balancing competing clinical demands against that of meeting the project’s aim and objectives. The additional pressures created by the project significantly affected the team’s ability in managing and balancing service and project needs. The Foundation of Nursing Studies provided a bursary that could be used creatively to support the project’s development; these funds were primarily utilised to enable attendance at the practice development workshops. In hindsight it would have been beneficial to have secured match funding from the Local Health Board to enable backfilling dedicated project time.

The feedback received from the specialist sleep practitioner in respect of the information booklet was highly critical. Initially the project team found it difficult to accept the comments, viewing them as hurtful, irrespective of how well intended they were. The team met and reflected on these and other positive comments before assimilating and revising the booklet. The outcome has been the production of information presented in language which is balanced and understandable; thus reaching the audience as intended.

Finally, the work stream has reviewed its progress and has reported that repatriating dispensing from community pharmacies to hospital pharmacies in the West and Central areas has resulted in significant savings in relation to the prescribing costs; work is on-going within the East. In addition a sleep training strategy has been implemented within the health visiting and disabilities nursing services. It is planned that the Child and Adolescent Mental Health Services (CAMHS) practitioners will be identified next to receive appropriate training once commissioned. It is anticipated that collectively these approaches will enable continued change in service delivery and prove to be cost efficient yet effective in improved outcomes for children and their families in the longer term.

**Conclusion**

The project was supported by the nursing and wider team within the child disability department; without this support the project would not have been viable. All the objectives have been achieved except for the piloting of a sleep telephone helpline. This objective changed with the involvement of the key nursing staff and involved establishing and running a dedicated nurse led sleep clinic. Clinics are now operating across North Wales on a weekly basis. Processes and pathways are constantly being reviewed and altered as new issues are encountered, for example the distribution and collection of sleep diaries in a timely way.

The project lead has responsibility for sleep service development for childhood disabilities across C&YP CYG and will formally review pan CPG service developments in 6 months.

On reflection the project team have gained an insight into some of the challenges practice change can produce. The skills and knowledge gained from attending the FoNS workshops and applying and utilising different approaches have enabled the project team to work with these challenges.
References


Acknowledgements
We would like to thank the parents who contributed to this project; their willingness to share their own personal experiences has given this project more depth and meaning. We would also like to thank the Foundation of Nursing Studies and the Burdett Trust for Nursing for their continued support throughout the stages of this project.
Appendix 1: Sleep Management Pathway
(based on Catherall, and Williams-Jones, 2011).

Meet Parents at Clinic

Collate base-line information

Explain importance of recording and provide a sleep diary and behaviour log

Analyse and graph completed sleep diary

Identify total mean-time sleeping and any trends in sleep pattern: sleep settling/sleep disturbance that indicate appropriate intervention. Discuss with parents/cares

Extinction

Sleep Restriction

Scheduled Awakening

Consider medication (dependent on family situation)

Review at regular clinic appointment

Collection of Sleep Diary at agreed intervals

Alter management strategies and consider medication if strategies are resistant to change

Repeat Review
### Appendix 2: Training Needs Analysis for Nursing Staff: Sleep Questionnaire Template

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Require Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you understand sleep cycles and disorders?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you use sleep hygiene assessments?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you use sleep diaries?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you use sleep behavioural logs?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you use sleep habit questionnaires?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you analyse sleep diaries and plot them on charts?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioural Approaches: Do you use or are you aware of the following approaches?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extinction: Graduated Non-graduated</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep restriction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scheduled awakening</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Faded bedtime (with or without response cost)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronotherapy</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 3: Behavioural Terms

For sleep settling difficulties

Sleep Hygiene: Developing consistent and robust pre and post bedtime routines.

Standard Extinction: This is where parents/carers totally ignore all bedtime disruptions – they put the child to bed and give no further interaction until the morning.

Faded Bedtime (FB): Involves determining the optimum time the child will go to sleep within a 15 minutes time threshold once put to bed. Once the child routinely falls to sleep for 4 – 5 consecutive nights the bedtime is set earlier each night thereafter until desired bedtime is achieved. The child is woken each morning at a set time.

Faded Bedtime with response cost (FBRC): As above, but the child is removed from the bedroom to a low stimulus environment (response cost) if not falling to sleep within the 15 minute time threshold. The child is returned to bed, usually at half hour intervals with the procedure repeated until the child falls to sleep.

Sleep Restriction: Similar to FBRC in its approach, but its main concern is determining the amount of actual time the child has sleeping rather than the time the child goes to bed. Once this has been determined the sleep worker will reduce the child’s sleep by 10% i.e. they will only be scheduled to sleep 90% of their sleep baseline. This will involve going to bed later; following FBRC criteria and fading bedtime to an agreed time at 15 minute increments.

Chronotherapy: Used to treat highly disruptive insomnia in adults – only one study in childhood ASD, but has promise. The approach involves systematically delaying bedtime and waking time each day, whilst maintaining regular day time routines. This routine is recommended when a child does not sleep at all over 24 – 48 hours.

For disruptive night waking

Graduated Extinction: Parents/carers are encouraged to spend increasingly longer amounts of time where they ignore their child’s ‘cries’ and ‘protests’. The aim of this approach is to fade the amount of time parents/carers spend attending to the child after waking; this is achieved by agreeing a time parents/carers will wait before going in to check on the child i.e. after 5 minutes. Parents will go into the child’s bedroom put them back to bed and leave and repeat this until the child sleeps. On subsequent nights parents will incrementally increase the time before going into the child’s room.

Scheduled Awakening: Baseline recording of awakenings determine optimum time of waking i.e. between 2.00 and 3.00 am. The parent/carer will be expected 30 minutes prior to the child’s expected waking, to gently rouse the child, but not enough to fully waken them. This act enables the child to re-enter a deep sleep state. Once the child meets four consecutive nights of non-waking the parents will fade the scheduled awakening incrementally over several weeks, usually on a variable ratio (VR).

Stimulus fading: An approach used to manage co-sleeping issues. This involves gradually removing the presence of the other person (stimuli) from the bedroom i.e. sleeping on a mattress next to the child’s bed and incrementally moving (over days, sometimes weeks) the mattress towards the door and out of the room.
Appendix 4: Feedback Form

Information Feedback Form

Re: Sleep Hygiene Leaflet

The information we produce is intended for parents and carers, so we would like to know your opinions on whether it meets your needs and what could be improved.

The form below allows you to tell us what you think of the leaflets. Any comments will be forwarded to the person who will be responsible for reviewing the document in question so that they can make any amendments.

Please circle your response

Question 1
Did you find the leaflets easy to read and understand?  
YES / NO
If not, why?

Question 2
Do you feel the leaflets contained sufficient relevant information?  
YES / NO
If not, what information was missing?

Question 3
Was the design and layout of the leaflets clear and well presented?  
YES / NO
If not, what changes would you suggest?

Question 4
Do you have any suggestions for how the leaflets could be improved?  
YES / NO
Your suggestions

Please Return to:
Appendix 5: Examples of Sleep Literature Developed

Top Tips to develop a healthy sleep routine

1. Be predictable. Keep day time naps to one hour (twice daily for young children) stop naps by 4 years of age.
2. Start early ideally when baby is 4-6 months old.
3. Allow your child to self settle in the cot/bed.

For further advice and support please contact your School Nurse or Health Visitor.

<table>
<thead>
<tr>
<th>SLEEP HYGIENE</th>
</tr>
</thead>
<tbody>
<tr>
<td>FOR PARENTS &amp; CAREGIVERS TO PROMOTE A HEALTHY SLEEP ROUTINE FOR BABIES &amp; YOUNG CHILDREN.</td>
</tr>
<tr>
<td>NHS GIG</td>
</tr>
<tr>
<td>NHS GIG</td>
</tr>
</tbody>
</table>

NHS Centre for Nursing Innovation
Inequalities, Emotion, Empowerment
Babies under 6 months having

During the night, as little interaction as possible
night time feeds should be given

Stages of the routine.

Consistent and firm, routines
This may need to be repeated

If your child does not settle be

If your child fusses and leaves the room

As a general rule...

With age,

The amount of sleep your

Child needs varies and decreases

With age.

Sleep hygiene is a healthy

Sleep routine resulting in good

Quality sleep for children and

Sleep is a fundamental part of a

What is sleep hygiene?

Sleep problems faced by parents of

Sleep is one of the most common

Child development. Lack of

Healthy sleep routines?

How to develop a

Children need?

How much sleep do babies and young
do in the first 3 months

3-5 year olds need 10-12 hours

0-3 years need 12-14 hours

Sleeping in bed. This will enable

Bedtime routine should be the

Experience, story, and bed

Bedtime and stick to it

Decide on a age appropriate

Night time feeds

Longer periods (5-6 hours at a

bed means more tired

Routine.

By 6 months the neurons

Being unpredictable

Wake up with their routine

During the first 3 months

After the day, any longer will interfere

Hours (maximum 1 hour nap in

Sleeping in bed (including daytime naps).

Self-setting.

It is vital that your child falls

Sleep.

Sleep.

Sleep.

Sleep.
SLEEP BETTER

INFORMATION AND ADVICE FOR PARENTS AND CARERS TO IMPROVE SLEEP HYGIENE FOR CHILDREN WITH ADDITIONAL NEEDS
# Average Hours of Sleep Needed for age

<table>
<thead>
<tr>
<th>Age</th>
<th>Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 Years</td>
<td>11 1/2</td>
</tr>
<tr>
<td>5 Years</td>
<td>11</td>
</tr>
<tr>
<td>6 Years</td>
<td>10 3/4</td>
</tr>
<tr>
<td>7 Years</td>
<td>10 1/2</td>
</tr>
<tr>
<td>8 Years</td>
<td>10 1/4</td>
</tr>
<tr>
<td>9 Years</td>
<td>10</td>
</tr>
<tr>
<td>10 Years</td>
<td>9 3/4</td>
</tr>
<tr>
<td>11 Years</td>
<td>9 1/2</td>
</tr>
<tr>
<td>12 Years</td>
<td>9 1/4</td>
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<tr>
<td>13 Years</td>
<td>9 1/4</td>
</tr>
<tr>
<td>14 Years</td>
<td>9</td>
</tr>
<tr>
<td>15 Years</td>
<td>8 3/4</td>
</tr>
<tr>
<td>16 Years</td>
<td>8 1/2</td>
</tr>
</tbody>
</table>

*Taken from Lyn Quine “Solving Children’s sleep problems”*

This table serves as a guide, the amount of sleep each child requires varies particularly for those with additional needs.
## Sleep Diary

<table>
<thead>
<tr>
<th>Length of Daytime naps</th>
<th>Mon</th>
<th>Tue</th>
<th>Wed</th>
<th>Thu</th>
<th>Fri</th>
<th>Sat</th>
<th>Sun</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time went to bed in evening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time went to sleep</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time[s] woke in the night. What you did and time of re settling</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time woke in the morning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Sleep Hygiene

Sleep hygiene involves a regular and predictable bedtime routine each night. Good bedtime routines become even more important as children get older and are vital for children with additional needs. Communication aids such as schedules, symbols and objects of reference can be used to support their understanding of the bedtime routine.

You must be consistent for your child to learn the routine.

A calming ‘winding’ down period of approx 30 minutes should be introduced before starting the bedtime routine. The calming down period should not involve watching tv or using any computer devices such as ipads, phones and laptops.

Blue light produced from these items inhibit the body’s natural production of the sleep hormone ‘melatonin’.

It is vital that your child falls asleep in bed, this will enable self settling. If your child does not settle be consistent and firm, resettling with little fuss and leave the room. If your child objects you can stay by the bed but be don’t engage with your child or give eye contact. Each night gradually distance yourself from the bed.

Repeat the routine as many times as necessary and be prepared for disruptive sleep while introducing the new routine.

Be consistent and stick to it.

Use lots of praise and rewards when you see positive changes.
## Example of Sleep Hygiene

<table>
<thead>
<tr>
<th>TIME</th>
<th>ACTION</th>
<th>TIME</th>
<th>ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.00pm</td>
<td>Snack time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.30pm</td>
<td>Play time: In the garden / Outside activity-Walk / park</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.30pm</td>
<td>Activity: If computer games / TV or iPad are preferred activities then they should be accessed here earlier on in the evening.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.00pm</td>
<td>Tea time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.00pm</td>
<td>Quiet play</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.30pm</td>
<td>Quiet bath: Clean teeth and pyjamas on</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.00pm</td>
<td>Into bed / Story</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.15pm</td>
<td>Tuck in, say goodnight, lights out and leave the room</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
If you continue to experience difficulties and need further support please contact your paediatrician to discuss referral to a sleep clinic.

Sleep clinics will be held in Conwy and Denbighshire.
Appendix 6: Nurse Led Sleep Clinic Pathway

Sleep Clinic Pathway

Clinic appointment one:
- Conduct standard Sleep Assessment
- Provide 2-week sleep diary
- Arrange home visit (if appropriate)
- Arrange follow up appointment

Pre 2nd appointment:
- Receive and graph sleep diary
- Consider interventions
- Conduct any professional liaisons.

Clinic appointment two:
- Discuss Sleep Diary (Actigraphy) outcomes.
- Discuss, agree and write up the sleep intervention plan

Subsequent Clinic appointments (Maximum 6)
- Review progress of intervention plan, alter plan if necessary
- Offer telephone advice, if necessary
- Repeat base-line sleep diary, if necessary
- Refer on/back to paediatricians if sleep problem persists
- Plan exit