



# FoNS Improvement Insights

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

**Project team:** Chris Catherall, Service Manager; Angharad Davies, Community Sister; Laura Brewerton, Senior Healthcare Support Worker

**Duration of project:** December 2012 – December 2013

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

### Project background

The central childhood disabilities service in North Wales provides specialist assessment services for children/young people and their families, divided into early years (0-5 years) and school age (5-18 years). 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. Generally they are prescribed sleep medication, namely melatonin, as a first line treatment approach prior to referral to the 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.

### 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 and management of children with sleep disorders. This would include the use of a behavioural management as a first line approach, with a view to reducing the use of prescribed medication. To achieve this aim, the objectives of the project were to:

- Understand the training needs of staff in relation to sleep disorders
- Understand the carer and family perspective of living with a child with a sleep disorder
- Engage and work with the core nursing team to implement possible treatment options
- Develop 'sleep' literature for both parents/carers and clinicians and to get feedback on it

### Key activities and outcomes of the project

• Training needs analysis using a staff survey  
A survey of nursing and clinical psychology staff, which yielded a 69% response rate, was undertaken to analyse training needs. This analysis provided a valuable insight into current knowledge and practice that indicated staff's current training needs in relation to sleep management. This analysis enabled work streams to explore and commission appropriate levels of training for different groups of staff.

• Sleep training  
The training delivered by Sleep Scotland was considered to be the most appropriate for the learning disability nurses due to the curriculum and teaching methods. Thirteen nurses from across the localities expressed an interest in developing their skills in this area. They attended 5 days' intensive training over

a 3-week period in May 2014. The training was conducted via plenary sessions and small group role play. A follow up half day was held in July 2014 which enabled practitioners to present and discuss cases with a view to developing sleep counselling competencies.

• Parent stories  
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.

• Claims, concerns and issues  
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 initial plans to develop a telephone help-line to the establishment of a childhood disability nurse led sleep clinic.

• Nurse led sleep clinics  
The sleep clinics, which are run by the nurses who undertook the Sleep Scotland training, have been operating weekly in two localities since September 2014. The clinics enable nursing staff to meet families' needs specifically in relation to sleep issues. To support the nursing staff with the sleep clinics, the project leader has also organised a monthly case-discussion meeting that allows time to plan and discuss individual cases.

• Sleep information leaflet  
The project team have developed a sleep management information leaflet and booklet for families. The team 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. The booklet is now being given to families at the nurse led sleep clinics.

### Implications for practice:

- Patient/family stories are a powerful way of sharing experiences and may motivate staff to innovate
- Listening to and acknowledging staff concerns can help shape services and make them more sustainable
- Sleep may not be traditionally thought of as a nursing issue, but if care is to be truly person-centred, patients must be treated holistically

A full project report including references can be accessed from: <http://www.fons.org/library/report-details.aspx?nstd=64517>

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