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Counting Sheep: A collaborative approach to managing sleep problems in children and young people with learning disabilities and challenging behaviour.

Abstract

In response to the local need for advice and support for parents of children and young people with learning disabilities, a structured 3 week sleep clinic was developed by a community team who targeted a small group of parents and carers and provided individualised sleep care plans. The clinic was evaluated very positively by parents, resulting in an ongoing sleep clinic programme; and the procedure has been shared with another Disabled Children's Team. Further evaluation could be implemented to strengthen findings; however, it may be useful to share these initial findings more widely with other localities.

The authors present an overview of a collaborative approach to managing sleep problems in children and young people with learning disabilities and challenging behaviour.

Introduction

The Disabled Children's Team (DCT) is a multi-disciplinary team of professionals; comprising Community and Behavioural nurses, Social workers and Occupational therapists. The team has been in existence for approximately 14 years, the focus of which is to provide advice and support to children, young people and their families with issues arising from moderate to severe learning and/or physical disabilities.

The DCT receive high volumes of referrals from professionals and carers requesting advice and support with issues relating to sleep for children and young people with learning disabilities and the effects this has on the young person's mood stability, learning, management of behaviour and carer

resilience. Adlington et al (2006) and Freeman et al (2008) discuss the correlation between sleep disturbance in children and daytime behavioural difficulties and parental stress. Stores (2010) considered the negative impact of sleep disorder on the child's cognitive development. Historically the DCT have addressed these needs on an individual basis, which often meant that the child would remain on a waiting list until he/she is allocated to an individual Community nurse.

Development of the sleep clinic

The decision to develop the sleep clinic was twofold; not only did it allow for parents/carers to have the support of other people in a similar situation, but it also led to a reduction in the waiting time for support as the clinic allows as many as 8 families to participate at any one time.

Two nurses from the DCT began devising a programme in 2011, which looked at the prevalence of sleep issues amongst families with disabled children and how these needs are currently met. It was without doubt that some of the generic information contained within the clinic would be of benefit to parents/carers of none disabled children, however the main focus of the clinic was to address the additional need that the disabled child may have in relation to sleep and the ability of the family to respond appropriately and effectively to the need. For example; according to parental reports, children with Autistic Spectrum Condition (ASC) take more than an hour to fall asleep, endure periods of nocturnal awakening lasting more than 3 hours and exhibit excessive laughter, talking, screaming and playing within the bedroom. (Marlow, Krakowiak and Richdale 2006; cited in Richdale, 2013).

A meeting was arranged prior to the pilot clinic with the Consultant Paediatricians and Registrars. The proposed sleep clinic format was presented to this large group. A discussion ensued as to how the medical profession and the DCT currently address sleep issues for children and young people with learning disabilities. This approach is supported by Carr et al (2007), who suggest that the multimodal approach can have a positive effect on chronic sleep disorders of children with learning disabilities and can improve child and family health and wellbeing.

This resulted in an agreed pathway. When the need for sleep support was identified, usually at a paediatric consultation, the family would be directed to request a place at the sleep clinic. This was prior to medication being prescribed in most cases.

Likewise if the medics knew that parents and carers had attended the sleep clinic and implemented recommended strategies but still felt that medication was appropriate, this information could assist them in their decision making in terms of prescribing.

After considering the clinic content, delivery style, audience size and care planning. The following format was agreed:

- 3 sessions to run over 3 consecutive weeks, (during school hours)
- 2 hour sessions with an opportunity for a comfort/refreshment break
- A maximum of 8 parents
- Interactive delivery style, consisting of PowerPoint presentation, opens group discussions, role play and group work facilitated
- Centrally located to allow for easy parent access
- Individual sleep care plans to be provided following the last session.
- Follow up evaluation, 4 weeks hence

Full support of the DCT management was given as the clinic required considerable preparation time, delivery time, room booking and a small financial contribution for refreshments.

Prior to the pilot, home visits were made if families requested initial discussions and reassurance. Screening for appropriateness and sleep diaries were given out with the expectation they would be completed for a 2 week period, allowing for some initial raw analysis – at this stage the parent/carer responses were not considered.

Desired outcomes of the sleep clinic

Parents/carers will be able to:

1. Identify the biological, medical and environmental factors that are causing the current sleep/bedtime routine.
2. Track predictable behaviours by their child and consider how these are reinforced by the current situation.
3. Become familiar with a variety of sleep programmes/strategies and coping mechanisms

Clinic content

Week 1	Aims and objectives of the clinics outlined. Dispelling myths related to sleep disorders/conditions and use of language. Individual experiences of parents (note taking begins). Discussions regarding prevalence of sleep issues amongst children and young people with learning disabilities.
Week 2	Associated factors of sleep disorders presented - life limiting conditions, lack of parental resilience, stress/guilt, behavioural problems and separation anxiety. Resilience framework activity – parent/carer participation, specific to their own experiences, coping mechanisms.

	Draft individual sleep plan emerging, presented for group consultation.
	Homework – resilience activity worksheet
Week 3	<p>Feedback from homework – parent/carer responses discussed.</p> <p>Setting the scene for sleep.</p> <p>Teaching of social cues.</p> <p>Physical environment and its impact on sleep.</p> <p>Discuss the requirement for additional resources – PEC’s, social stories and visual timetables.</p> <p>Four cycles of sleep.</p> <p>Techniques introduced and discussed – ethical problems with controlled crying and Ferber extinction approach; gradual extinction and scheduled waking.</p> <p>Use of medication.</p>

Care Plans

Throughout the clinic, notes were taken on each young person’s sleep problem, associated issues and parent/carer responses. These notes then underpinned the individualised care plan that each parent received. They focused on the specifics and took into account, for e.g., other siblings the parent/carer has to consider, is the size of the support network/ availability of another parent in the home to support the plan. The plans were inclusive of the clinic content with clear guidelines on setting the scene/bedroom, social cues through to what a parent should say and the tone of their voice. These plans were developed immediately after session 3 and sent to parents, alongside a copy of the power point.

“What if it goes wrong” Section

The care plans were positive and preventative in nature, however it was acknowledged that reactive strategies cannot be ignored. By the nature of children and young people, boundaries will be pushed, especially if parents/carers are implementing a new bedtime routine. Each plan therefore had a final section of “*what if it goes wrong.*” They were a range of guidelines included in this section, for e.g. what to do/say if your child gets out of bed, how to resettle your child if they wake during the night and how to react when your child is deliberately trying to gain your attention, to name but a few. It was paramount that parents/carers had this section in order to continue with the plan and accept that there will be challenges along the way and to “react” appropriately and feel empowered at the same time.

Ethics

One of the main ethical issues which arose from the sleep clinic was the need to educate parents/carers about popular, but potentially harmful techniques, for example controlled crying and Ferber extinction. These techniques involve leaving a child to cry for pre-determined lengths of time with the aim of teaching a child to “self-soothe”. Critics of the techniques such as Gerhart (2004) argue that self-soothing does not occur; the child learns that when she cries, help and comfort do not come. Further, leaving a child to cry affects brain development and may predispose an individual to a heightened stress response, resulting in an increased risk of poor mental health in later life. In terms of ethical theory, leaving a child to cry challenges the principles of beneficence and non-maleficence. These principles are concerned with the doing of good and doing no harm respectively (Beauchamp and Childress, 2013). The child’s communication method (crying) is ineffective in meeting her needs and so she experiences both the absence of good and harm. The sleep clinic provided parents with information and alternative techniques so that they could make

informed choices about the way that they responded to their children's sleep problems; and so promoted parental autonomy.

Evaluation and feedback

The evaluation session was arranged a month after the clinic had ended. It was felt that that was sufficient time to implement the plans. This session was probably the most enlightening; for both the facilitators of the clinic and the parents/carers. They were all very keen to hear each other's stories, offer advice when things had not gone quite according to plan congratulate each other on their successes. It was also an opportunity for the facilitators to discuss further strategies that might be of assistance; an approach supported by Durand (1998) who recommends that a large range of interventions are necessary for children with special needs. Parents/carers also completed an evaluation form which had been devised to obtain constructive feedback on all aspects of the clinic. The feedback was extremely positive, highlighting the outcomes of the clinic being thoroughly met by all, parents/carers happy with the venue and style of the clinic and the feeling of relax and comfortable within a small group. Some personal comments were noted;

"I don't usually like speaking out on course, but this one was different, nobody judged me and the other parents were so supportive."

"It's made me realise that I have created the problem, but I'm much more in control now and things are so much better"

All the parents/carers stated they would recommend the clinic to other people.

Facilitator Self-Evaluation

Although the parent/carer feedback was very positive, it quickly became apparent that there was a cohort of parents that were unable to attend due to the timing and their work commitments. An evening clinic was then arranged to meet this need. This held 6 working parents and was again, very successful and insightful for them.

Sleep clinic programme

The clinic now runs approximately 3 times per year and times/dates vary to meet the wide range of parent/carer needs.

The style and content remains the same, as the non-judgement facilitation method is not only effective for delivery, it encourages parent/carers participation, assists relaxation and allows for open and transparent discussions. It could be argued that parents/carers go on a journey of self-awareness and reflection; this is facilitated in a sensitive way, as some parents/carers have become emotional during the clinic and it is imperative that by the end of each session they feel supported and positive.

A final note, the sleep clinic was entered into the South West Yorkshire Partnership (NHS) Trust awards for innovative practice in 2012, and received a “highly commended” award.

Recommendations

The evaluation of the sleep clinic programme could be developed to include objective measurements of sleeping patterns and behaviour before and after the sleep clinic. Such evaluation would provide stronger evidence for the efficacy of the clinic. However, community teams for children with a learning disability may find the approach outlined in this article useful based on the very positive user feedback. Indeed, the DCT have already shared their practice with a neighbouring team, indicating the usefulness of wider dissemination.

Conclusion

Responding to the local need for sleep advice and support in the families of children with learning disabilities and challenging behaviour, the DCT designed and implemented a successful sleep clinic. Over a 3 week period the clinic equipped parents/carers with individualised information, tools and

support to manage and cope with their child's personal sleep issues. Feedback from parents/carers was positive and has resulted in an ongoing sleep clinic programme.

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