Addressing sleep disturbance in young children with developmental delay

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Annie has worked as an occupational therapist in a variety of paediatrics settings in Australia and overseas. She completed her Masters in OT (by research) in 2003 having studied sleep disturbance in children with autistic spectrum disorder and the use of a waterbed. Since 2004 Annie has worked for Early Childhood Program (Disability South Australia) on a special project called 'Sleepwise'. She maintains a special interest in addressing sleep disturbance in children and adults with developmental disabilities.

Summary

Adequate sleep is essential for all children's health and development. Children with developmental delay experience additional challenges in their daily lives when their sleep is disturbed. Parents and carers may experience emotional and physical stress as a result of their child's sleep-disturbed nights. In 2004, Early Childhood Program (ECP), Disability South Australia, in response to this identified need, developed the Sleepwise approach. Apex Foundation for Research into Intellectual Disability Limited awarded a one-year grant to this Program in 2005 to further develop the Sleepwise approach. The grant was used to conduct and evaluate the Sleepwise workshops for parents and carers across the metropolitan regions. This article will overview the Sleepwise approach and the results of the evaluation.

Introduction

Children between the ages of two and six years of age spend up to 50% of their time asleep, therefore we need to understand and observe our children's sleep as part of their overall development. Sleep is a natural but complex process that does not always occur without difficulties. Parents and carers often report their child's sleep as inadequate, disrupted, of poor quality or non-restful. (The term *parents* is used in the remainder of this article to include carers.) The lack of adequate sleep can impact on their child's moods, behaviour, learning and health. Research has clearly linked sleep disturbance in children to increased stress levels

in families (Mindell and Owens, 2003). Parents' own sleep quality and quantity is directly impacted by their child's sleep problems (Lopez-Wagner, Hoffman et al, 2008: Meltzer, 2008).

Sleep disturbance is highly prevalent and persistent in children with a significant developmental delay, who often present with a combination of sleep problems (Stores and Wiggs, 2001). A recent population-based study found that sleep problems were reported in 32% of typically developing children, 46% of children with developmental delay and 53% of children with autism spectrum disorders (ASD) (Krakowiak, Goodlin-Jones et al, 2008). Certain groups may present with higher prevalence of sleep problems such as over 80% in children with Rett syndrome. Certain diagnostic groups present with a higher occurrence of different types of sleep disturbances. For example, children with ASD present with greater difficulty in getting to sleep and staying asleep while children with Down's syndrome present with more sleep-related breathing disturbance. Children with developmental disabilities who have had sleep difficulties over many years and who continue to present with sleep disturbances, often require support and intervention to assist them in developing better sleep patterns.

Children with developmental delay experience additional challenges in their daily lives when their sleep is disturbed. There is an increased probability of such behaviours as hyperactivity, mood swings, lethargy, aggression and self-injurious behaviour. Some children with additional problems may also benefit in other ways from gaining adequate sleep. For example, children with epilepsy are less likely to have a seizure after restful nights. Therefore, promoting positive sleep practices and addressing sleep disturbance in children with developmental delay is important in a prevention role.

Some parents may think their child's sleep disturbance is related to their diagnosis and that successful intervention is not possible. However, there is a growing body of knowledge and research into the various approaches or methods that can reduce sleep disturbance in young children with developmental delay. As the Table below shows, promoting sleep hygiene including consistent bedtime routines and environments can assist many children with developmental delays to learn to self soothe and sleep independently (Jan, Owens et al, 2008).

Developing positive sleep practices:

- Set a regular time for bed each night and wake-up time each morning. Keep the time consistent between weekdays and weekends.
- Establish a predictable and consistent bedtime routine of approximately 30 minutes with calm activities, with the last part of the routine occurring in the child's bed.
- Keep the hour before bedtime relaxing, as too much activity can keep a child awake (over-aroused). Time spent outside and exercise during the day assists sleep at night.
- Avoid large meals close to bedtime. However, a small healthy snack before teeth cleaning may assist in settling to sleep. Avoid foods with caffeine (such as chocolate) for at least 4-6 hours prior to bedtime. Reduce or eliminate night feeds.
- Provide a comfortable bed 'nest', warm to cool in temperature, reduced noise level and make as dark as possible (night light if needed).
- Aim for the child to fall asleep by themselves in the same place as where they sleep all night.
- Daytime naps need to be geared to the child's age and development. Very long naps, extra naps or naps in the late afternoon can result in a child sleeping less at night.

Positive Sleep Practices

Interventions for sleep disturbance will depend on the type or combinations of sleep problems. Behavioural, sensory and communication strategies can assist children with settling to sleep and night-waking difficulties (O'Connell and Vannan, 2008). Consistent use of interventions is likely to improve the child's sleep to some degree, to the benefit of the child and the other family members. Medical intervention may be required for specific problems such as the surgical removal of the adenoids or tonsils for sleep related breathing difficulties. Other interventions include the considered use of melatonin, medication for specific sleep disorders (epilepsy, REM sleep disorder), diet considerations, light therapy (Stores and Wiggs, 2001: Jan, Owens et al, 2008) and the use of a waterbed (O'Connell, 2003). Anxiety and depression can also contribute to sleep disturbance in older children and may respond to stress management, relaxation training and cognitive behavioural therapy.

Development of the Resource Manual

In 2004 a special project was funded to develop a Manual called *Sleepwise – Positive Sleep Practices for Young Children with Developmental Delay* (O'Connell, 2005). The manual contains resource material for allied health workers to conduct three educational workshops for groups of parents. The workshops cover typical sleep, positive sleep practices, types of sleep disturbance and strategies to reduce sleep disturbance. The material has been developed to cover developmental, sensory, behavioural and communication aspects of sleep. It is not intended to promote one particular intervention strategy but to provide parents with a wide range of information. The resource can also be used to support individual families with children (2-6 years of age) with sleep disturbance. Included in the manual is a CD with OHP/PowerPoint slides for the workshops, parents' booklet, sleep diary, sleep interview, sleep plan and sleep stories for children. The manual also contains guidelines for individual sleep plans and reference material for allied health workers.

Pilot workshop

In 2004 a pilot parent group was conducted to trial Sleepwise. Feedback from the parents was essential for the development of the Manual and the approach. Families attended three two-hour educational workshops held every second week. A two-week sleep diary was completed between the first and second workshops and an individual sleep interview was conducted (normally in the home) between the second and third workshops. Following the workshops families commenced their own unique sleep plan in their own time frame with ongoing support and monitoring from their allied health workers for several months.

Implementing the Sleepwise Approach

In 2005, a one-year grant from the Apex Foundation for Research into Intellectual Disability Limited, allowed parents' workshops to be conducted across four regions of metropolitan Adelaide. Flyers were posted to families in each region and Early Childhood Program (ECP) workers approached individual families where parents considered their child's sleep a concern. Two ECP workers presented each series of workshop in their regions. A total of 27 families were listed to participate in the Sleepwise workshops.

The families listed to attend the Sleepwise workshops had children aged 1 year 10 months to 7 years 1 month. There was a range of diagnoses from global developmental delay (14), ASD (8) and other syndromes (5). The children presented with a range of sleep disturbances including difficulty going to sleep, night-waking, early waking, cosleeping with parents,

constipation, extended day naps, continued night feeding, still sleeping in a cot and bed-wetting.

Sixteen parents attended all three workshops. The most common reasons for non-attendance were illness of parents or their child or family stresses. Some families needed additional support to attend workshops such as the provision of taxi vouchers. Two families indicated their initial intention to attend but did not. ECP workers felt that attending workshops can be intimidating and stressful for some parents.

Parents chose a wide range of strategies in their sleep plans. Communication strategies included use of visual prompts, visual cue cards with sequential pictures about the bedtime routine, and sleep stories with such topics as going to sleep, staying in their own bed or sleeping in different places such as at grandparents'. Sensory strategies included aromatherapy, weighted quilts and pillows, massage, torch, wrapping tightly in a blanket (as used with infants), music, video, white noise, sensory blanket, totally dark room and security objects. Behavioural strategies included gradual distancing of parents, ignoring, gradual ignoring (or checking method), and timetable scheduling. Parents also determined short and long term goals. For example, families may work on settling to sleep before night-waking, or reducing night feeds before behavioural strategies for night-waking. Goals were also set in consultation with the allied health workers to determine an acceptable positive change in sleep patterns rather than perfect sleep. For example, improvement in settling could be considered 100% successful if achieved within 30 minutes on five out of seven nights per week.

Parents varied greatly in the timing of starting a sleep plan. Many families started making changes following Workshop 1 based on positive sleep practices while other started the sleep plan up to ten weeks post workshops. The average time to achieve short-term sleep goals was 8 weeks. These families spent more time in preparation (for example writing sleep stories or organizing sensory strategies), waiting until their child's health improved or family circumstances settled (for example, after a house move). Two families did not write a sleep plan while two other families have deferred the sleep plan (one felt their child was too young and the other planned to build a new bedroom to separate siblings). Most families needed support and monitoring by their allied health worker for three months post workshops.

Case Study: Shane

Shane is a five-year-old boy with a chromosomal syndrome resulting in global developmental delay. Shane's mother Alice attended three Sleepwise educational workshops in 2009. Shane's sleep problems were identified through a two-week sleep diary completed by the parents and a sleep history interview conducted in the home.

Alice reported Shane's 'going to bed' behaviour as difficult 1-3 nights a week with settling taking more than an hour. From the sleep diary Shane had taken less than an hour to fall asleep 10/14 nights with more than an hour 4/14 nights. The time taken to settle to sleep ranged from 15-200 minutes. Day naps particularly impacted on settling time.

The parents had tried to establish a bedtime routine, often stayed with him until he fell asleep and had removed the globe from his bedroom light to stop him turning the light on and off. Parents felt frustrated by his repetitive behaviour of coming in and out of his room, throwing objects and crying if they didn't stay with him. Night-waking was not a concern although early waking before 6 a.m. was recorded (previously woke at 4.30am). Shane had adenoids and tonsils removed two years earlier with improvement in breathing and reduction in

snoring. Shane also moves his legs particularly when falling to sleep. From the sleep diary it was established that Shane needed on average 9 hours' sleep which is below the average hours for typically developing children of the same age. After the conclusion of the third workshop a sleep plan was written which can be seen below with the progress that was achieved.

Sleep Plan	
Short-term goal:	To fall asleep in own bed within one hour.
Long-term goal:	To fall asleep in own bed within 30 minutes. To increase total sleep time.
Things to do during the day:	Reduce / eliminate day naps (limit to 30 minutes maximum). Outside active play after school for 1 hour.
Bedtime routine:	Set wake-up time at 5.30 - 6.30 a.m. and bedtime 8.30 p.m. for an average of nine hours' sleep. Aim to increase sleep time once sleep pattern established. Regular night routine of outside play, dinner, bath at 6.30 pm, TV. Start bed routine at 8 pm with milk, clean teeth then to bed. In bed read story with parent then lights out.
Sensory strategies:	Turn lights out and use a torch with rechargeable batteries while settling to read book (to encourage melatonin). Give a small massage while in bed and give vibrating pillow as settling.
Behavioural strategies:	Dad to sit / stand at bedroom door (ignoring with parent's presence) until Shane asleep.
Communication strategies:	A sleep story about the bedtime routine was written with Shane's name and read each day at least once. A four-picture visual sequence of the night routine was shown to Shane each night. Parents used same verbal instruction 'bedtime', 'back to bed'.
Reinforcement:	Shane added a star to his chart in the morning for 'great sleeping' and parents gave lots of praise.
Other strategies:	Consider iron, calcium, magnesium supplement for restless legs – discuss with doctor. Consider melatonin if settling time remains over one hour – discuss with doctor.

Progress	
Week 1:	Shane enjoys reading his sleep story. Achieved bedtime at 8.30 p.m. and falling asleep within 30-60 minutes every night. Dad standing at the door. Waking in the morning at 4.30 a.m. 2/9 mornings but generally later than 5.30 am. Decision to start using star chart.
Week 3:	Going to bed between 7.30 and 8.30 p.m. and falling asleep within 10 minutes. Waking at 6.30 a.m. Story being very effective. Shane needs the 1-hour play outside after school to assist in sleep. Parents pleased with progress.
Week 12:	Established 7.30 p.m. bedtime while on holiday and Shane began to sleep for 12 hours. Continues to go to sleep at 7.30 p.m., settling easily and sleeping on average 11 hours. Short and long term sleep goals achieved.

Conclusion

Sleep disturbance is highly prevalent and persistent in children with developmental delay and requires early intervention. Also, promoting positive sleep practices can prevent further sleep disturbance. Families vary greatly in their readiness to start a sleep plan and in their preference of intervention strategies. The Sleepwise approach offers a wide range of strategies that can be tailored for individual children and their families. Positive changes in sleep patterns have been seen in individual case studies with families who have often needed support from their allied health workers for several months.

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