

# New Opportunity

Issue 12

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## A sleep pathway for disabled children

*Research revealed that 82% of parents with children with disabilities experience sleep as a problem in their family, few receive any support at all. Gudrun Limbrick, a trustee of the Handsel Trust, describes the Trust's proposed solution.*

Research published by the Handsel Trust early in 2007 demonstrated that as many as 100,000 families in England and Wales felt that they had a problem with sleep. Only a handful of the 400 families we surveyed had received any form of support related to their sleep problem.

The sleep problems experienced impacted on the whole family - the child with disability him or herself, the parents' ability to work, the parents' relationship, the physical and emotional well-being of siblings and their schooling.

Some parents described children who simply would not go to sleep. Other children woke constantly through the night despite the best efforts of other family members. Some parents described children who had to be checked constantly through the night.

The Handsel Trust, supported by Miranda Parrott as an independent consultant, worked last year to develop a

solution to this enormous sleep problem in the families of children with disabilities. Based on discussion with parents, practitioners and academics, we have developed a sleep pathway. The pathway provides a means of recognising those families with sleep problems and structuring intervention.

The sleep pathway was presented at a seminar in the summer of 2007. At the seminar were a range of practitioners - specialists in sleep and other frontline practitioners. Also present were representatives of Sleep Scotland who have run a very effective country-wide sleep service for several years. Between us, the details of the sleep pathway were discussed, ways forward presented and ideas brainstormed. The following pages of New Opportunity present the discussion and the pathway itself. We would, of course, welcome any further comments and discussion.



**Sleep? What's that?**  
*the incidence and impact of sleep problems in families of disabled children*  
By Gillian Cowdell & Miranda Parrott

Full results from the survey of families in England and Wales and a review of recent research and other materials on the subject of sleep and children with disabilities.

Details are on the last page of *New Opportunity*

## New Opportunity

*The newsletter of the  
handseltrust*

*The Handsel Trust  
promotes effective  
support for families  
who have a child with  
disabilities/  
special needs.*

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# Developing our Sleep Pathway

*These discussion notes were made following the Handsel Trust seminar on the Sleep Pathway in July 2007. The Pathway itself is shown on the next page.*

The two-stage Pathway has received general approval and the sleep initiative in general has been welcomed because it has helped raise awareness, has provided good opportunities for professional networking and has identified good practice. Level I intervention is welcomed as a way to get some relevant support to a large number of families right from the start and Level II is welcomed as skilled intervention by trained Sleep Practitioners for a smaller number of families that can, when necessary, open doors to relevant specialists. It is felt that effective sleep intervention at either level:

- will be proactive
- is dependent on an ongoing relationship and dialogue between professionals and individual families
- will be an integral part of a co-ordinated response to a family with a disabled child/young person/adult
- requires training and resources
- will be person- and family-centred and empowering
- will take a holistic view of the causes
- will be tackled as an issue in its own right rather than automatically thinking in terms of 'respite'

## Sleep... What helps?

**The Handsel Trust is working with Jasia Beaumont of the Southampton Sleep Service to produce a manual for practitioners working with families of children with disabilities.**

**The manual, following on from *Sleep? What's that?*, will cover issues of assessment, recognising sleep problems, encouraging good sleep hygiene for families presenting with sleep problems, appropriate referrals and useful resources.**

**In terms of the Sleep Pathway, the manual will be a resource for Level 1 practitioners.**

**We are working towards publishing the manual in 2008 and will provide details in future issues of *New Opportunity* and on our website.**

**[www.handseltrust.org](http://www.handseltrust.org)**

solutions

The seminar produced a long and varied list of causes of sleep loss in families with a disabled member including bedtime routines, diet, medication, particular conditions/syndromes, pain, circulation, noise, siblings, work patterns and accommodation. This is yet another reminder to us all that we cannot make assumptions when we meet a family and that we should be prepared for anything and everything. Since the seminar we have been looking at some way of categorising these causes that could inform holistic thinking and training for the stages of assessment, intervention and review. The following structure is offered here in the hope that someone will offer something better or point to some relevant work already completed:

- Sleep interventions that focus on the disabled person. (Can include medicine, psychology, psychiatry, pain, incontinence, etc.)
- Sleep interventions that focus on the family. (Can include attitudes, routines, work patterns, consideration of siblings, etc.)
- Sleep interventions that focus on the physical and social environment. (Can include neighbours, street lighting, bed, bedroom, etc.) Possibly, there are two categories here rather than just one.
- Sleep interventions that are a mix of the above.

We recognise that some of the various elements in the above structure cannot be entirely separate entities (e.g. sibling considerations and bedrooms) but in our view the draft structure remains valid as an attempt to enable professionals to keep the big picture in mind.

The proposed title 'Sleep Practitioner' was accepted with some comments about the merits of Sleep Practitioners functioning as a pair at Level II. Costs and professional availability were cited as possible issues. The paired idea follows effective practice in Southampton's Sleep Disorder Service, acknowledges that 'two heads might be better than one' in some challenging situations and provides for a skill mix in which 'medical' expertise can be coupled with 'behavioural'. We will see how this works out in practice.

The proposed Sleep Intervention Pathway remains as a valid broad outline and the feedback at the seminar has produced a wealth of valuable material that will inform our future work. Modifications will be made and details will be added to the basic Pathway during the development of training programmes and assessment schedules. After that, the Pathway inevitably will be shaped to fit family needs, service structures and available resources in each locality. Our experience in the UK shows us that it is not realistic to offer a rigid model of intervention with no built-in flexibility.

We would like to thank sincerely all of the people who have contributed so far to our sleep initiative and to assert that knowledge, ideas and comments are still welcomed.

# Handsel Trust Sleep Intervention Pathway



## LEVEL 1 SUPPORT

### Prevention and basic intervention: key features

- Offered by practitioners from both universal services and disability services from all local statutory, voluntary and private agencies.
- Probably informal and occurs as a natural part of the practitioners contact with the child and family.
- An holistic checklist (developed as part of the Handsel Trust pathway) is available to the practitioners that refers to behavioural, medical and other issues.
- The practitioner has access to information resources to offer to the family.
- Intervention at this level helps the family acknowledge the situation and invites them to think about possible causal factors.
- Parents and practitioners can agree on relevant action points, e.g. bedtime routine, visit to GP, bedroom/ accommodation issues.

if necessary



## LEVEL 2 SUPPORT

### Intervention by trained Sleep Practitioners: key features

- Structured interview by two trained Sleep Practitioners (SPs) who have different skills but are competent between them to explore the whole picture to include:
  - Behavioural issues
  - Medical issues
  - Other issues
- SPs are part of the local integrated children's service or trust and already operate within multi-disciplinary teams. Their approach is family-centred, flexible, needs-led and uses a family partnership model.
- The interview uses a schedule developed as part of the Handsel Trust pathway.
- Following the interview the SPs make necessary and agreed links with other services which know the child/family and fit into any keyworking, care co-ordination, TAC systems.



## Outcome:

- An holistic, co-ordinated and written action plan with formal strategy for review.
- This can include referrals to other local or regional services for more specialist investigations or interventions.
- SPs will themselves provide interventions as agreed in the plan and carry the responsibility to ensure the plan is carried out and reviewed with the family.

# Sleep: the impact of problems on families

*The following stories are based on recent conversation with families about their experiences of sleep. Details have been changed to protect the privacy of the families concerned.*

Duncan is 14 years old and has a diagnosis of ADHD as well as other medical problems. He lives with his mum and sister who is currently studying for her GCSEs.

Duncan has difficulty settling to sleep and wakes constantly through the night. Once awake he likes to get up. Often he has left the house and goes wandering the streets in the night. His mum can't sleep because of the fear of where he will go and what he might get up to while he is out. She worries particularly about who he might meet while he is out.

His night-time activities and his mum's attempts to contain him usually wake up his sister and, as a result, she has missed school and her studies are suffering.

Mum feels at the end of her tether. Her son is taking medication but this has not impacted on his activities at night. She would like locks on all the doors and windows so that she could lock them from the inside and curtail her son's tendency to wander but she does not have the funds to pay to have them fitted. Ideally, she would like respite so that she can spend some time with her daughter.

She talks of years of disturbed sleep making it difficult to cope with life during the day and her physical health is suffering. She is very stressed and perhaps depressed.

Michelle is 16. She lives with her parents and her older brother. Unlike many of the children we come into contact with about sleep issues, Michelle sleeps very well. Instead, the sleep problems lie with her parents.

Michelle has a hydrocephalus and has a shunt. Every night for the past 17 years, her parents have checked on her constantly throughout the night to ensure that the shunt is working as it should. Between them, her parents check on Michelle several times every night.

After years' of disturbed sleep Michelle's parents are exhausted. As they have got older, their own sleep patterns have changed and both are now finding it more difficult to get back to sleep after the nightly checks. Between checks Michelle's mum worries about her daughter and other issues in family life and some nights finds it difficult to sleep at all some nights. She is stressed and tired and so finds it difficult to cope with what each day presents. She feels her relationship with her husband is suffering as is her relationship with her son. Her husband is tired at work and too exhausted when he comes home to do very much other than sleep.

Michelle's mum won't consider any kind of sleeping remedy as she wants to be alert in case her daughter has any problems. She finds the thought of trusting respite carers, including family members, too difficult to contemplate.

## Learning from each other

**At the Handsel Trust we are collecting a dossier of family stories about how sleep affects their lives.**

**Our aim is to encourage greater understanding of sleep issues and disabled children. Many of these stories (in anonymous form) appear on our website. To read the stories or contribute to them, please visit**

**[www.handseltrust.org](http://www.handseltrust.org)**

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## **IMPROVING PRE-SCHOOL SUPPORT FOR CHILDREN WHO REQUIRE MULTIPLE INTERVENTIONS WITHOUT OVERLOADING SERVICES AND PRACTITIONERS**

**Co-facilitated by Peter Limbrick and Shirley Young to explore the dilemmas and pressures that arise as service providers work towards effective support for children and families within current resources and staffing levels**

**Wednesday 30<sup>th</sup> April 2008**

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**Menzies Pinewood Hotel, Handforth, South Manchester SK9 3LG**

*This hotel is 4 miles from Manchester Airport and 4 miles from M60 Junction 3. There is a train service from Manchester*

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**Information and Booking forms also available from: Interconnections, Parks Farm, Clifford, HR3 5HH**

**Tel/fax: 01497 831550 E-mail: [peter.limbrick@icwhatsnew.com](mailto:peter.limbrick@icwhatsnew.com)**

# RESOURCES ON FAMILY SUPPORT

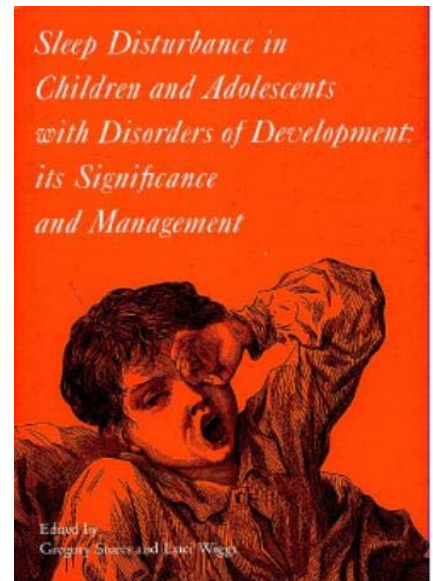
## Sleep Disturbance in Children and Adolescents with Disorders of Development: its Significance and Management

Edited by Gregory Stores and Lucy Wiggs  
Mac Keith Press, 2001  
ISBN 1 898683 24 7

This book, in recognition of the fact that sleep disturbance is extremely common in disabled children and adds significantly to the burden of care, reckons that it was (at the time of publication) the first book specifically addressing the management of sleep problems.

The book is formed of a series of 30 essays, looking at all aspects of sleep in relation to neurodevelopment disorders such as Prader-Willi Syndrome and Down Syndrome; non-neurological paediatric disorders such as asthma; and psychiatric disorders such as ADHD and depression.

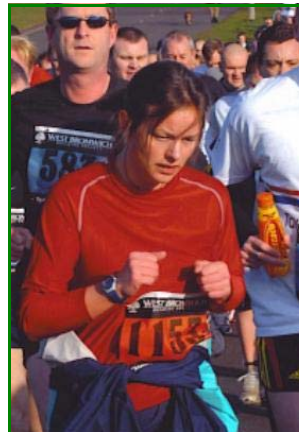
Its main audience is intended to be child healthcare professionals but it will also be of interest to anyone wanting to broaden their understanding of sleep disturbance.



## Sign up to New Opportunity!

If you have not received this issue of New Opportunity directly from the Handsel Trust, please drop us an email with your email address and we will make sure you get all future issues. *Because of escalating costs, we are no longer able to send out New Opportunity free by post.*

[handsel.trust@virgin.net](mailto:handsel.trust@virgin.net)



## On the run...

Gudrun Limbrick, one of the trustees of the Handsel Trust has foolishly agreed to give the London Marathon a go this April. Should she make it round all 26.2 miles, all proceeds raised will go to the sleep work of the Handsel Trust. Visit [www.handseltrust.org](http://www.handseltrust.org) to sponsor her.

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- I would like to continue to receive **New Opportunity by post**. I have enclosed a cheque for £5 and my address is below
- Please send me a copy of **'Sleep? What's that?'**. I have enclosed a cheque for £15.00.
- Please send me details about future conferences
- Please remove my contact details from the New Opportunity mailing list. I do not wish to receive any further mailings from the Handsel Trust.

Please make cheques payable to the Handsel Trust. Thank you.

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Alternatively, visit [www.handseltrust.org](http://www.handseltrust.org) and do it all online

## [www.handseltrust.org](http://www.handseltrust.org)



The Handsel Trust has now redeveloped its website. The website is now much easier to use and has a wide range of information to download. Purchasing books on the site is now possible - credit card payments can be made safely.

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