

Talking sleep

Handsel Trust

This article by Peter Limbrick of the Handsel Trust, excluding the summary, first appeared in the SLD Experience, Issue 48, Summer 2007.

Summary

The Handsel Trust Sleep Initiative comes from an awareness that many families who have a disabled baby, child, teenager or adult member suffer disturbed sleep to the detriment of everyone in the family. This article introduces the Trust's Sleep Survey and then describes the tremendous impact on families who are sleep deprived.

'My daughter has cerebral palsy and epilepsy. She is thirteen years old now and I don't remember not being tired in that time.'

This parent was responding to a request from the Handsel Trust for information about sleep, or the lack of it, from families of children and young people with disabilities and special needs. Why were we asking? We were aware that many of these families had sleep problems but we did not know how many nor did we have a clear idea of how lack of sleep impacted on families. We decided to find out. The parent above e-mailed us two years ago when we were in the early stages of our sleep initiative and since then we have learned a great deal. Now we are even more concerned than we were then.

The Sleep Survey

In addition to receiving letters, phone calls and e-mail messages from parents we also conducted a survey with help from the Family Fund and Contact a Family. With questionnaires and some interviews our researchers surveyed 375 parents from the Family Fund database. It is a measure perhaps of the importance of the issue that we received these 375 responses from a mailing of only 750. A 50% return suggested to us that we had touched on a very important subject for families. The Trust has recently published *'Sleep? What's that?'* by Gillian Cowdell and Miranda Parrott.* This combines a literature survey on the subject with our survey findings. We now estimate that well over 100,000 families in England and Wales are suffering from lack of sleep and are not being offered help. We know too that lack of sleep can impact on every member of the family and on all aspects of their lives. Some families do not survive. (Our survey did not include Scotland or N. Ireland. Scotland has a charity called Sleep Scotland that offers valuable support to families in Scotland and has trained a number of professionals to work as sleep counsellors south of the border. We have no reasons for thinking the situation for families in N. Ireland is significantly different from that in England and Wales.)

The Handsel Trust is working with other organisations to explore how we can get more help to more families in the future, with the keen understanding that surveys and research studies that sit on shelves do not benefit children or families. But 100,000 families represent a formidable mountain of unmet need

and change does not happen quickly. In the meantime we are working to raise public and professional awareness of the issue of families who are suffering disturbed nights and long-term sleep deprivation. In the Trust we see disturbed sleep as a largely hidden problem because it does not get talked about enough – by parents or by professionals. And because it does not get talked about the problems are not acknowledged and help is not offered.

If we all start talking to each other about lack of sleep then it will not be a hidden problem anymore and a space will be created in which change can begin to happen. When professionals raise the issue with the people they are supporting they will almost certainly find that what they learn will add to their understanding of the baby, the child, the young person, the adult, the family. Professionals who encounter hidden sleep problems in this way will surely be prompted to explore what sort of help is at hand in their locality. When parents talk about their sleep issues to professionals they might well feel supported just by having their problem listened to and acknowledged. When parents share their sleep issues with other parents they might decide collectively to add sleep to the list of issues they want to address with their local service providers. So talking about sleep is a start and it is something we can all do.

The impact of significant sleep issues in families

What is the impact on families when there are significant sleep issues? What are you likely to hear when you ask about sleep? Very many parents have told their stories to the Handsel Trust and the following eight invented families are representative of them. (I have used the word 'parent' to include anyone in a parental capacity.)

Family A: The parent says lack of sleep has been a serious issue over the last fifteen years and says thank you for asking because no one else has – ever. This brings us back to the hidden problem; parents not mentioning sleep issues because they do not imagine any one can help and professionals not thinking about sleep when they do their assessments of need. Parents struggle on as best they can and professionals remain unaware that they have missed a vital piece of the jigsaw. This parent is relieved to be

describing her situation to a genuinely interested professional and for a few hours feels her load is lightened a little.

Family B: The parent says lack of sleep is a long-term issue and that someone did try to help them once but it came to nothing and they have not seen them since. On closer questioning the parent explains that they were given a programme of some sort to do with bed-time routines but that they could not keep it up and the professional had nothing else to offer. They elaborate, a little cynically, 'They gave us a bedtime routine to follow and we tried it a few times. Yes, he had his tea OK. Yes, he had his bath OK. Yes, he tolerated a story OK. Then he ran screaming round the house for three hours.' It seems to me that sleep interventions should mirror other family-centred interventions for children with disabilities and special needs by having a foundation in a genuine partnership between professionals and parent. There needs to be a helping relationship, an individual response to each unique child and family and time to explore all of the issues.

Family C: The lone parent is very willing to talk over the phone about the family's lack of sleep but does not want anyone to come to the house. Why? Because she is ashamed of the sink estate she and her teenage children have just been moved to. She had to move out of her home because her neighbours complained to the council about the nightly shouting and screaming. She adds that her new neighbours do not care about the noise at night because they are all drunk or on drugs. She fears for her family and is ashamed to have visitors.

Family D: The parent reports serious sleep issues and is worried that her children might lose out at school because there are nights when none of them get much sleep. The child with special needs never sleeps more than a couple of hours and when he is awake he keeps his older brother and sister awake. Then, when he gets to school he often dozes off when he should be learning. The teacher in the last class used to let him sleep but the new teacher rings home and wants him to be collected. This mother adds that by the time she gets to school he is awake again but feels she has to take him home anyway. The other boy and girl often get to school late because the family has slept in after a bad night. The teachers at the boy's school are understanding but those at the girl's

are not and she gets into trouble time and time again. This exhausted mother lies awake in the small hours (even when her children are asleep) and worries that none of her children have proper opportunities to learn and do well at school. She stares at the ceiling worrying what will become of them.

Family E: The parent reports that there are frequent disturbed nights with her pre-school child but that this is only one of her problems. She and her partner have just one child, a little girl of two years who was premature and has many problems. She has visual and hearing impairment, motor delay, learning difficulties and epilepsy. She is fed through a tube into her stomach and needs a suction pump to help keep her airways clear. During the day and night she will cry frequently with no cause that her parents or anyone else has discovered yet. With frequent health crises and stays in hospital this little girl's life seems to hang on a thread. Her mother is all too aware that it is her watchfulness and her special expertise with the complicated medications and caring regimes that keeps her child alive. But she is exhausted. At night when the child cries she tries to comfort her. When the child sleeps she dozes lightly listening for a fit or choking. She feels she has a double duty at night to keep her daughter safe and calm and to let her partner sleep so that he will be fit for work in the morning. She has very many duties during the day; visiting various special clinics, caring for the child, encouraging her to play between the bouts of crying, pursuing the housing department for better accommodation, fighting to get proper therapy and pre-school education for her daughter and performing the usual domestic tasks as best she can. She says she is too tired to cope. She is always running on empty and she does not know how much longer she can carry on like this.

Family F: These parents, both in their fifties, have a teenage son who has severe learning difficulties, incontinence and a physical condition that means his position has to be changed during the night. He usually sleeps quite well once he settles off at about 11 p.m. but if he does wake he screams with fear and needs comforting for up to an hour before he can settle off again. His parents take it in turns to be on duty at night to change his position and, when necessary, his pyjamas and sheets. They

discovered some years ago that if they slept in separate bedrooms the one who was off duty had more chance of getting some sleep. Once every three months or so their son spends a couple of nights in a local short break unit (once called 'respite' unit). Neither parent wanted him to go at first because they felt the staff would not know what their son needed, but eventually they were persuaded and off he went. He responded well from the first and seemed to like going but it took a long time for his parents to relax enough so that they could sleep while he was away. Now it is a very welcome break for everyone and both parents feel it allows them to recharge their batteries. The only problem is that the staff at the unit have just said he will not be able to go so often in the future because there are too many families for too few spaces. There have even been some reports in the local paper that the unit might have to close down because of financial cutbacks. These devoted parents cope by trying not to think about the future.

Family G: This mother is on her own with three young children, two boys and a girl. The girl is the youngest, has special needs and seems to be able to go for days without sleep. Instead of sleeping she rampages around the house, bangs doors, switches on TV and stereo, turns water and gas taps on, throws things at the windows and climbs on the cupboards. She has had extensive examinations but no cause has been found for her inability to sleep – and no cure either. Medication was tried. It worked for a short time and raised everyone's hopes but then was ineffective. A psychologist had lots of helpful suggestions that all came to nothing. It was at that point that the children's father left home. He insisted that he loved his children and loved his wife but that he could not carry on without sleep. He was always too tired to do his job properly and saw a real prospect of being demoted or sacked. He had already been overlooked for an expected promotion. He said that to survive he needed to work and to work he needed to sleep. He could see no other option but to leave his family. The mother is on antidepressants now and she and the children struggle on in a life that is often as bizarre as it is chaotic. When the daughter is awake, everyone is awake. When she sleeps, everyone sleeps - day or night, week day or weekend. She is usually calmer when out of doors so all four are often to be found walking to Tesco's at three in the

morning. Better to be out shopping than keeping the neighbours awake again.

Family H: This mother becomes very serious and thoughtful when asked about sleep issues. She says that her son, who is now fourteen years old, hardly slept for the first six years and life became almost impossible for her and her partner. The health visitor, the G.P. and the other professionals around her young son seemed not to take the problem seriously on the basis that babies often keep their parents awake. By this logic the parents should not expect any special help. Fortunately, a paediatrician eventually took them seriously when he saw how desperate the parents were and how close the family was to falling apart. He referred them to someone who came to their home, listened to their concerns, observed their routines and suggested a plan of action. This professional was able to maintain a close involvement to support the parents as they explored the suggestions. Gradually things changed for the better. Their son still has the occasional disturbed night but by and large sleep is not the big problem it was in the first years.

The work of the Handsel Trust

The Handsel Trust has learned that professionals who can help a family with sleep issues in this way can come in many guises; for example, they might be a specialist health visitor, an occupational therapist, a clinical psychologist or a paediatric nurse. They can help because they have taken a special interest in sleep and have studied the subject, perhaps as an elective part of their professional training or as post-qualification professional development. Other members of these same professions might well not have any expertise to offer. In England and Wales, where all support services for children with disabilities and special needs are patchy in the extreme, a few families will be lucky enough to have access to a trained sleep counsellor or a sleep clinic. Without wishing to state the obvious, it is worth making the point that even trained professionals will not be able to help if their job does not allow them sufficient time to spend with each family in need.

At the Handsel Trust we feel privileged to have had so many parents take time out of their busy lives to tell us their stories and we believe the stories can help inspire change in professional assumptions, attitudes and awareness. But what

else can the Trust do apart from raising awareness? We have learned from some families and from some service providers and researchers about what can help in practical terms. Using this valuable information we are designing an intervention pathway that will provide a flexible template for children's services that want to provide for this unmet need in their locality. We are greatly helped in this by other organisations and there is a growing network of interested professionals we are consulting as our plans develop. Our pathway will be staged – offering basic support to the majority of families and more specialist interventions when the issues are more complex. Our model will include appropriate training for existing multi-disciplinary professionals so that they can support families they meet in their normal work as well as training in sleep counselling for professionals helping those families who require more specialist support. To stay in touch with these developments readers are invited to visit our website and, if they have a special interest, to join the professional network.

With more than 100,000 families out there with unmet need, many professional in this field (and some readers of this journal) are working with sleep-deprived children or sleep-deprived families – perhaps without realising it. This can mean that the benefit of their work is diluted to a greater or lesser extent and that the child's and young person's opportunities for play, education and leisure activity are spoiled. The Handsel Trust's appeal is for us all to consider that lack of sleep might be a problem for every child and family we meet in our work. But we will not know for certain if we do not ask. Talking sleep can help.

**Sleep? What's that? The incidence and impact of sleep problems in families of disabled children.* By Gillian Cowdell and Miranda Parrott. Published by the Handsel Trust. 2007.

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