THE MANSFIELD PROJECT

PROVISION OF POSTURAL CARE AT NIGHT WITHIN A COMMUNITY SETTING : A FEEDBACK STUDY

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INTRODUCTION

This paper describes a service to provide postural care at night for children, and feedback from them and their families. The children were felt to be at risk of developing distortion of body shape in the long term and are provided with therapy by the Children's Rehabilitation Service in Mansfield, Nottinghamshire.

In 1976 Fulford and Brown published a seminal article which suggested that:-
"The "squint baby" syndrome and the "windswept" child syndrome in children with cerebral palsy are stages of the same syndrome and that in both the deformities are caused by the effect of gravity on an immobile growing child,..... Asymmetrical deformity should therefore be amenable to physiotherapeutic intervention..... As the "windswept" cerebral palsied child can develop some of the most severe deformities seen in cerebral palsy, it is important that asymmetrical deformities should be prevented"

Over the last twenty years advances have been made in postural care, particularly care provided during the day, with orthotics, wheelchair seating and static seating improving along with devices for assisted standing. The availability of new equipment, patented as "Symmetrisleep," provided comfortable, versatile support and control in the lying posture for use at night and became a significant supplement to the already existing day time postural care program.

It was perceived that abnormality of tone and movement often caused the children to lie in destructive postures for long periods at night and that these habitual lying positions very often became recognisable as the pattern of fixed distortion of body shape as the child grew older. The distorting effect of gravity on body shape of young babies and their need for supported positioning has long been recognised. (Bellefeuille - Reid 1989, Fulford and Brown 1976, Hallsworth 1995, Turrill, 1992).

The many hours available for intervention at night were regarded as an opportunity to introduce significant therapeutic benefit for the following reasons. Firstly, during the night when the child is asleep, the body is less influenced by perverse muscle tone, making it more susceptible to corrective forces. Secondly, as the body is lying flat, with carefully supported symmetrical positioning, gravity can be used to mould the body in a beneficial way rather than distorting the body as it presses downwards on an asymmetric lying posture or on the upright posture. Thirdly, during the night the child does not have other demands made upon them as they do during the day, for instance during those few hours that are spent at school, which are vital as the short key period of their lives during which they are entitled to resources to provide them with their basic education.

The complexity of sleep disturbance amongst children with neurological dysfunction was recognised, with behavioural and social issues complicating the incidence of increased arousal time, latency of rapid eye movement (REM) sleep and decreased REM sleep time, fewer gross body movements during sleep, reflux, epileptic arousals and sleep apnea syndromes of both central and obstructive origin. (Ferber 1986, Kotagel et al 1994, Okawa 1986) Medication to address the numerous problems of the child adds another layer of complication to the issues involved.

The children included in the Mansfield Project live in a variety of community settings, mainly with their parents, so that the commitment to twenty-four hour intervention involves active co-operation of the family. This paper will describe methods that were used to identify children at risk, the establishing of a register which quantified need, how funding was obtained for equipment and clinical input, the training and support given to parents and how the service was implemented. Initial evidence, based on the first year of involvement by thirty-one families, is presented as a foundation on which therapists can build clinical practice.

IDENTIFYING AND QUANTIFYING THE PROBLEM

The Children's Rehabilitation Service in Mansfield, served by North Nottinghamshire Health Authority, recognised the importance of creating a service to provide postural care to maintain body symmetry for those children found to be at risk of developing deformity in the long term. A register of these children was established in order to quantify the problem to be solved and the resultant financial implications. As the solutions to these problems require the co-operation of many agencies and in order to make criteria for inclusion to the register accessible to parents, clinicians, health and social service managers and educationalists, the following five simple factors, were used to identify the children.

The Mansfield Checklist of Need for Postural Care

1) Does the body stay in a limited number of positions?
2) Do the knees seem to be drawn usually to one side?
or inwards? or outwards into a "frog" posture?
3) Does the head seem to turn mainly to one side?
4) Does the body tend to flex forward?
or extend backwards? or both?
5) Is the body shape already asymmetric?

This checklist would be used in combination with detailed knowledge of clinical and social factors to devise local policy.

OBTAINING FUNDING

The following bid for funding was devised by Ann Peters, the Children's Rehabilitation Manager.

CHILDREN'S REHABILITATION SERVICE
CASE OF NEED FOR AN INTEGRATED POSTURAL CARE SERVICE

The importance of twenty-four hour positioning has long been recognised by therapists in the care programmes of children with neurological dysfunction.

Management of a child's posture has been achieved during the day by:
a) Corrective seating in school and home provided by Education, Social Services and / or wheelchair services.
b) Classroom and home positioning programmes i.e. use of standing frames and side lying boards.
Funding for these items comes from a variety of sources, including Social Services and charitable monies.

However, a child's life typically consists of approximately
8,760 hours in the year
1,140 hours in school
7,620 hours with the parents
3,640 hours in bed

c) It is clear that treatment strategies will be ineffective if the child is left to adopt destructive postures during the hours spent in bed. Night time positioning advice has been given by therapists advising parents to use domestic equipment such as towels and pillows for support. However, this has been found to be ineffective in many cases as the equipment moves as the child assumes different positions in bed. New treatment options are now available to give tailored support to meet individual children's needs.
This support should be introduced before damage and distortion of skeletal structures takes place, but can also benefit children who are already asymmetric.

There is no precedent for long term consequences of an integrated service to provide parents with the training and equipment enabling them to implement twenty four hour postural care in the community. However, in our professional opinion, based on clinical experience there would be the following long term benefits in providing such a service.

* Maintenance of symmetrical body postures
* Reduced risk of contracture and deformity
* Improved function
* Reduced long term need for surgery, all too often we see expensive surgery being carried out, only for the child to return to the lack of postural care which contributed to the problem in the first place.
* Reduced need for complex , expensive pieces of equipment for the older child, ie moulded seating, matrix seating systems etc.
* Health and emotional gain for the child, improved quality of life, improved sleeping patterns, reduced pain and increased life expectancy.

Contd.

* Health and emotional gain for the extended family, early results indicate that children who previously had to have frequent changes of position during the night or disturbed nights are sleeping through the night in a fully supported position.

The current number of children at risk living in North Nottinghamshire served by Central Nottinghamshire Healthcare are:-

School	0 - 10 years old	10 - 19 years old

The costs of systems range from £400 - £700 each depending on assessed need. There is no funding currently identified to address this need.
Total initial cost £ ??
The team are keen to audit the results of this service, if this bid is supported.
A training and support scheme for parents, along with continuous monitoring will be included in the total package of care offered by the Paediatric Rehabilitation Services.

The bid was supported fully by the Health Trust.

TRAINING AND SUPPORTING PARENTS

Within the Service parents are acknowledged as experts in their own child with the therapist's role defined as being to empower parents by presenting information and practical help in friendly terms and by being available for discussion and support. Despite resources of the Paediatric Service being stretched, every effort is made to train and support parents by all therapists working within the service. Due to the intimate and emotive nature of interventions associated with sleep and its influence on family life, therapists involved need to be comfortable with a non-judgemental approach to parents. Therapists who do not enjoy working closely with families of all types will not find this area of work rewarding.

Particular responsibility is taken by Lynne Hewitt, a physiotherapist, whose values and attitudes pervade the Project. Hewitt is able to bring valuable insight, empathy and credibility to the role by virtue of the fact that she is also the mother of a child who requires postural care during the day and night. Training and support is perceived by Hewitt as a key to successful treatment as the equipment is so versatile that it is only as good as the user's detailed understanding of the principles of postural moulding, the particular distorting tendencies within their child's body and how to counteract those tendencies. In some cases solutions arrived at through common sense, self teaching or previous knowledge are already in place but in many cases the user's understanding is only as good as the training and support they receive from therapy services.

John Goldsmith , who invented the equipment and pioneered its use with all age groups, has acquired extensive experience with older individuals who have severe problems with body shape. This experience tells us that the way to achieve successful postural care at night is to work from the individual's habitual position, to support that position and make them comfortable, so reducing abnormalities of tone. Once this first stage has been achieved it is considered that subtle changes in the use of support can be made to coax the body towards a more symmetrical position. This slow, gentle approach has been found to be more likely to succeed, in the long term, than more urgent, demanding intervention.

Most mistakes are made in the pursuit of too much change, too soon with too little training and support. Experience tells us that simple solutions tend to be better accepted and implemented than more complicated arrangements.

Formal Parent's Workshops are held with a syllabus contained in slides and written material. (Goldsmith 1997, 1998a) Discussions and "hands on" sessions take place to give parents a theoretical and practical basis for their involvement. Parents are taught that therapy is a two pronged attack with the first, underlying foundation being postural care and the second being development and maintenance of function.

It is acknowledged that development and maintenance of function, often the high profile aspect of therapy, can all too frequently be less successful when there is a lack of awareness of the need for postural care and the destructive nature of unsupported habitual postures at night creating distortion of body shape.

The following terms are identified in theory and used appropriately with regard to the parent's own children:- "destructive postures" which, once identified, may become otherwise known as "bad postures". The alternative "supported neutral postures" are devised, photographed and discussed and may become identified as "good postures". (Illustrations of unsupported and supported postures)

The concept of “postural moulding” is described as the ability to use carefully devised, symmetrical positioning for long periods of time at night to influence the shape of the child. The effects of destructive postural moulding, particularly of the chest are identified.
These terms become part of the parent’s vocabulary and they are able to identify different postures in their own children.

Individual appointments are kept both in schools and out patient departments, home visits are carried out when possible to ensure that every effort is made to support the parent enough so that they are able to comply with the child’s needs for treatment. A Postural Care Diary is used to co-ordinate home and other agencies with compliance levels reported to be at least as high amongst parents as amongst professionals.

All the usual differences still apply between different parent’s natural ability to comply, along with all the usual difficulties that parents face when trying to come to terms with their child’s disability and cope with the practical problems of life. In some cases elements of the intervention were unsuccessful, specific details of these cases are included in the section describing results of the feedback study.

The parents and children in these cases continue to receive support tailored to their needs and the opportunity to have another try is always on offer. However, in many cases good postural care becomes as much a natural habit as washing up. Or as one mother said “I could no more leave my son lying in a bad posture in bed than I could go to bed without cleaning my teeth.”

IMPLEMENTING THE SERVICE

Mistakes were made in the first stages of implementing the service. Funding to supply equipment became available within a short period of time coinciding with the end of the financial year. Training and support networks were not fully in place and although there was not necessarily a need to prescribe the equipment immediately, natural enthusiasm for a treatment regime which influences such a significant number of hours in the child’s life meant that, with the benefit of hindsight, the assessment process and supply to the first families took place too quickly.

A crisis of confidence took place about two months after the first supply period of about six weeks, during which time a proportion of the families came close to giving up on the concept. These results are detailed in the feedback section. Having learnt from this experience it is recommended that training and support infrastructure is in place prior to supply of equipment. If therapy services are to maintain credibility it is also recommended that if awareness of the need for postural care is awakened in the parents that equipment is available to supply that need.

COLLECTING EVIDENCE

When an individual has multiple disabilities, often including difficulties with communication combined with extensive medication programmes, the complexity and intimate nature of sleep disturbance calls into question the validity and relevance of highly technical scientific analysis of sleep. This is because extraneous variables within the subject and their family are often very difficult to understand much less control.

Technical scientific investigation often has its place in the development of evidence based medicine, but as parents have an encyclopaedic knowledge of the multitude of factors affecting body shape and sleep behaviour of their child it would seem advisable to give their opinions status as scientific evidence. When "parent compliance" is widely acknowledged as an important factor in implementing treatment regimes it makes sense to listen to their viewpoint.

This study has concentrated on canvassing and accurately documenting the opinions of parents and users. A questionnaire was devised and feedback collected, talking to the first families to be supplied with equipment, who were also available for interview. Mainly parents and carers took part and the questionnaire was designed with them in mind but, with modifications to questions, the children themselves were interviewed whenever it was felt to be appropriate.

The following sections were devised in order to elicit as comprehensive and honest feedback as possible. The respondents were told that the purpose of the questionnaire was to learn from their experiences and they were encouraged to add comments freely to each section with positive and negative comments made equally welcome.

SECTION ONE: ABOUT THE USER

This section seeks to identify the respondent's understanding of the need for postural care, postural difficulties of the child in unsupported lying, and any other difficulties that the child may have with sleeping.

The following are results from the first 31 interviews.
28 individuals are still using the system
1 has been out of the system but her parents aim to try again in the near future.
2 are no longer using the system.

The subjects were Male - 15 and Female - 16

Their age ranged from 9 months to 19 years.

1 .1) What were the reasons for your child needing Symmetrisleep at night?
This question gives an indication of the effectiveness of training.

Reasons for Symmetrisleep Postural care - 27
Other - 3
Unsure - 1

Examples of the responses given when asked about the reasons for the Symmetrisleep:

*To keep him straight.
*Because of her Scoliosis.
*He was always uncomfortable and needed turning every hour.
*She has a severe lumbar scoliosis with all five Lumbar affected.

*I have a crooked spine and it is to help that.
*We want to keep her straight and see the system as a 'prevention rather than cure' treatment.
*He does not sleep well and it is also to help with his stiffness and spasticity.
*He sleeps better in the system, if he does not sleep well he has to come into bed with us so an improvement in his sleeping pattern is beneficial to the whole family.
*To try to improve her position at night.
*We thought that it would help his posture and curved spine.
*We think of the system as a form of physiotherapy.
*The sleep system was needed to address the problems of keeping her hips and back straight.
*She had surgery to correct a Scoliosis and needed the Symmetrisleep for follow up.
*The system is used so that he does not have to sleep in his brace.

1 .2) When your child was unsupported and you went to get them up in the morning, did you find them in a typical position?

Typical position Yes - 26
No - 4
Do not know - 1

If yes, able to give description of typical position Yes - 25
No -1

Examples of the descriptions given:

*On his back with his legs 'frogged' and pulled up to his chest.
*When on her side her hips and legs fall to the left, as though she is twisted at the hips like a corkscrew.
*He was often on his side but he tended to move around a lot in bed.
*Curled up on her left side.
*On either side, depending how he was left at last turning, in the 'foetal' position.
*When she is on her side she flexes forwards into a ball, but when on her back her legs 'frog'.
*On her stomach, curling round to the left.
*On her right hand side with the lower half of her body falling round further to the right.
*He slept on his side in his mother's arms at first, then he would move under the covers and finish on his back.
*On her back with her legs over to the left.
*On his right side, but with his shoulder flat, with his knees over to the right hand side.
*Banana shaped. On her back with her knees drawn to the right and her back bent to the right.
*On his left side, flexed forwards like a banana.

1 .3) In your opinion, can your child lie in a straight position without support?

Able to lie straight without support? Yes - 18
No - 13

1 .4) If they cannot lie straight please circle the main difficulties, do they:

tend to flex forward?
tend to extend backwards?
tend to curl to the right?
tend to curl to the left?
do the legs tend to "frog"?

Difficulties experienced	Tends to flex forwards - 6
	Tends to extend backwards - 2
	Tends to curl to the right - 4
	Tends to curl to the left - 6
	Legs tend to 'frog' - 7
	Other - 15

Examples of other difficulties experienced:

*She / he pulls her legs up and then they go over to one side - 5
*Tends to flex forwards and brings his knees up into a ball.
*She looks straight but I know that in actual fact she is not.
*She always turns her head to the left.
*He seems to twist round in the middle.
*She tends to extend backwards with the top half of her body and her left leg comes over her right.

1 .5) Does your child have any other problems with regard to position or movement in bed at night.

Positional Problems	Yes - 21
	No - 10

Examples of comments:

*Due to her breathing difficulties she has to use an apnoea alarm.
*She sleeps with her mother as she needs turning so often during the night due to getting uncomfortable easily.
*Whilst at a friends house recently, without the Symmetrisleep, she extended backwards and fell out of bed.
*She often gets pain in her right leg.
*She could roll from her back onto her side but then could not get back onto her back so she would need turning. She also moved around the bed at night and was at risk from falling out.
*She gets hot and uncomfortable easily.
*She used to wake continuously as she was not comfortable.
*He experienced discomfort in his hips and legs and due to this did not sleep for very long at all.
*She used to wake and need turning during the night when she got uncomfortable, although she still does she is now only turned once.
*She gets hot but that happens with or without the Symmetrisleep.

1 .6) Please describe any other problems your child may have with sleeping in general.

Sleeping Problems Yes - 19
No -12

Examples of comments:

*None, other than those associated with her breathing difficulties.
*She has difficulty getting to sleep. When she is at her grandmothers she sleeps through the night but she never does this at home.
*She is a good sleeper and although she probably wakes in the night she does not seek attention.
*He wakes often during the night. He cannot have any form of sedation as it may react with his Epilepsy medication and affect his already poor muscle tone.
*She has no sleeping problems as such, only the fact that it was difficult for her to sleep when she was so uncomfortable.
*As a family we had not had a full nights sleep for a long time. She was never comfortable and often cold.
*She has breathing difficulties and coughs a lot in bed.
*She usually sleeps very well no matter where she is.
*He wakes up if he has difficulty breathing and once awake it is difficult for him to settle again.
*She is on medication to help to calm and relax her before she goes to bed at night.
*He is now more comfortable in bed but he still has no sleeping pattern as such.

SECTION TWO: ABOUT USE OF THE EQUIPMENT

Respondents were asked whether they felt their child was sufficiently used to the equipment for them to make a judgement as to how the child was responding to its use. If they felt confident to answer, a five-point scale was used to rate the following aspects of the user's response to the equipment with two grades either side of "about the same" for each aspect. Question six enquires about the respondent's perception of likely effectiveness of intervention as the child grows.

2 .1) Does the user sleep in a straighter or less straight position?

Rating of position - In a much straighter position - 19
In a straighter position - 5
About the same - 5
In a less straight position - 0
In a much less straight position - 0
Could not answer - 2

Examples of comments:

*But then she was not that bent anyway.
*Straighter when the system is holding her but she can get her legs out of it
*The positioning is not quite right yet though.

2 .2) Does the user sleep better or worse?

Rating of sleep Sleeps much better - 3
Sleeps better - 8
About the same - 13
Sleeps worse - 1
Sleeps much worse - 0
Could not answer - 2

Examples of comments:

*He is awake for about the same amount of time during the night.
*She does not wake as often as she used to.
*Initially he slept fine, for six hours as opposed to one. As time went on however he slept less and less in the system and ended up sleeping for longer out of it.
*Her sleep seems 'deeper' in the system.
*His sleep is dependent on how well he has fed during the day and whether he needs feeding during the night.
*She slept better for the first few nights but then she refused to sleep in it again prefering to sleep in my arms.

2 .3) Is the user's mood in the morning more cheerful or more distressed?

Rating of mood in the morning
Much more cheerful - 0
More cheerful - 5
About the same - 21
More distressed - 1
Much more distressed - 0
Could not answer - 4

Examples of comments:

*He / She is always cheerful / grumpy in the morning.
*She used to be tired and grisly but now she is happy and a lot more supple.
*He wants feeding straight away and gets distressed if he is not fed quickly enough, his mood does not really have anything to do with how he has slept.
*Her mood has little to do with how well she has slept but whether or not she is happy with what she has to do that day.
*He sleeps downstairs on his own and occasionally gets frightened if he hears noises outside but if he has had a good nights sleep then he is more cheerful.

2 .4) Does the user has problems with high muscle tone / spasms / tightness / tight muscles?

Problems with muscle tone:

Yes - 26
No - 5

2 .4 a) **If the user has problems with high tone, are they more relaxed or more tense in the morning?**

Of those with muscle tone problems:

Much more relaxed - 2
More relaxed - 17
About the same - 9
More tense - 0
Much more tense - 0
Could not answer - 3

Examples of comments:

*She is now loose in the mornings whereas before she was quite tight.
*She has high muscle tone in general but her ham strings were especially tight, this was made worse when her legs were 'frogging'. Before we used the system in the mornings she would be so stiff you had to 'unfold' her.
*First thing in the morning she is quite relaxed but she quickly stiffens up again.
*She has fluctuating tone, periods of high tone then periods of far too low tone.
*We did not use the system long enough to notice any change in his muscle tone but he is generally very tight.
*She is now more relaxed but she also takes Baclofen.

2 .5) Does the user have problems with chronic pain?

User has problems with chronic pain:

Yes 8
No 23

2 .5 a) If the user has problems with pain, are they in more or less pain in the morning?

Of those who experience pain

In much less pain - 1
In less pain - 3
About the same - 2
In more pain - 0
In much more pain - 0
Could not answer - 2

Examples of comments:

*It is painful for him if he has to sleep in one position every night so his position is alternated between having his legs up and down.
*He sometimes has pain in his hip and the back of his knee is painful, however it is mainly sitting that affects this.
*She does not have any pain since they started using the system as she is far more supple.
*He gets back ache from sitting in his wheelchair all day but he does not suffer from pain as such.
*She suffers from pain in most joints but we did not use the system long enough to notice any difference.
*He suffers pain occasionally, due to operations.

2 .6) How do you think use of the support system will affect the user's body in future years?
The general affect on the users body in future years.

Beneficial - 28
No affect - 0
Detrimental - 1
Other - 2

Examples of comments:

*If we can get it right then it will be of benefit. At the moment however we cannot get it right so we will have to wait and see.
*It will help prevent him from getting deformities.
*Hopefully it will keep him straight and that is my main aim.
*We are hoping that it will stop her shape from getting worse, she has already had to have a new mould as she is straighter since we have been using the system.
*His position should be a lot better, we don't want him crumpled up.
*If it carries on being as effective as it is at the moment then it will keep her body the shape it is now. If they had not had it then her back would have a very bad curve.
*If it can keep her straight then it will obviously be of benefit.
*It will hopefully make me straighter.
*Using it now will be of benefit, her muscles will be used to being stretched and straight. It is a prevention rather than cure treatment.
*At the moment he is 2" shorter on one side. We hope to correct his body.
*I hope that it will maintain her intact hips and contribute towards keeping her back straight as she has a slight curve.
*It all depends upon whether we can get it right. If we get it right then it has to be of benefit.
*If her contractures became fixed she would lose the use of her right lower lobe of her lung which would have serious consequences due to her combination of C.P. with myotonic dystrophy and bouts of pneumonia. She was positioned from the age of three using diving weights and teddy bears. I am unsure as to whether she would still be here if she had not been straightened at night. Without the system her left hip would have dislocated.
*It will help to keep him a lot straighter.
*She sleeps in the same position now as she did before the system but now she is supported. I wish we had had it years ago as then the surgery on her back may not have been necessary.

SECTION THREE: GETTING USED TO THE EQUIPMENT

This section gives information about the experience gained by families with time scales for usual responses and comments about support services.

3 .1) How long have you had your Symmetrisleep system?

3 .2) Do you think a satisfactory arrangement and position have been achieved?

3 .3) How long did it take to come to this arrangement?

3 .4) Is the user used to the equipment?

3 .5) How long did it take for the user to get used to the equipment?

Time for arrangement and to get used to the system:

(3.1)	(3.2)	(3.3)	(3.4)	(3.5)
12 months	Yes	12 months	Yes	1 week
12 months	Yes	few days	Yes	Instant
12 months	Yes	3 months	Yes	3 months
12 months	Yes	2 to 3 weeks	Yes	Few days
12 months	Yes	Ongoing	Yes	2 weeks
12 months	Yes	6 months	Yes	6 months
12 months	Yes	9 months	Yes	9 months
12 months	Yes	6 months	Yes	Instant
12 months	Yes	3 months	Yes	very quickly
12 months	Yes	At set up	Yes	Straight away
12 months	Yes	Straight away	Yes	Straight away
12 months	Yes	1 week	Yes	2 nights
12 months	Yes	Quite a few months	Yes	> 6 months
12 months	No	N/A	Yes	2 to 3 weeks
12 months	No	N/A	Yes	Could not say
11 months	No	N/A	Yes	Days
10 months	Yes	2 to 3 months	Yes	2 -3 months
10 months	Yes	5 months	Yes	2 nights
9 months	Yes	3 months	Yes	Instant
9 months	No	N/A	Yes	4 weeks
8 months	Yes	At set up but ongoing	Yes	Instant
6 months	Yes	6 - 7 weeks	Yes	3 - 4 months
6 months	Yes	2 weeks	Yes	Could not say
6 months	No	N/A	Yes	Days
5 months	Yes	3 weeks	Yes	3 weeks
5 months	Yes	2 to 3 weeks	Yes	No of weeks
3 months	Yes	Set up	Yes	Instant
2 months	Yes	only just got there	Yes	2 months

Examples of comments:

*He got used to the equipment side of things straight away but the resultant loss of independence and privacy due to his movement being restricted at night is still causing distress.
*We needed the mattress changing but once that and the positioning were done things were fine.
*He was fine when the positioning was sorted out.
*We had 2 weeks when everyone was upset because she did not like it. It took a lot of fiddling and practising to get used to it.

*After three nights we gave up, she simply did not want to know.
*We tried her on her back but that did not work. She got used to it within days of being on her side.
*He has the system in the same bed as his older brother and sister, as long as they are there then he is fine.
*It was a huge change for him from his mothers arms to a bed on his own with the Symmetrisleep so it would be difficult to say how long it took exactly.
*It took quite a few weeks because I found it uncomfortable at first.
*The only difference in her sleeping behaviour was when we tried the kneeblock which was unsuccessful.
*It took three months. As soon as the positioning was right she settled into it straight away.
*At first he would get distressed as we put him into it but he was fine within a couple of weeks.
*He took to it straight away as he seemed so much more comfortable.

3 .6) Following assessment, what support have you had to help you use the equipment?

The number of people who were able to recall using support services were as follows:
28 were using face to face contacts with Lynne or the school physio. (varying in number from 1 to "about 10")
12 recalled home visits
19 recalled support telephone calls (varying from 1 to "about a dozen")
23 identified a telephone number, which they could use for help and support
2 identified other forms of support, "Parents Workshops" and "family"

Examples of comments:

*I have been in to see Lynne at school a number of times.
*Support from the school physio., who asks how we are getting on with it and gives encouragement and support.
*I had a lot of support from my parents who in turn were supported by Lynne.
*There is a daily opportunity for contact with Lynne via a home contact book.
*We have been to see Lynne and know that we can call on her at any time.
*Until September there was none and you really had to complain before things were done.
*It often takes a long time to sort problems out and if they are not sorted out quickly, progress that has been made is easily lost.
*What happens when she leaves school? What if things need changing or replacing?

3 .7) Do you think you would be helped by further support?

Yes - 27
No - 4 (3 not in the system at present)

Examples of comments

*We couldn't get it any better, we can do it with our eyes shut but we would need help to review it after surgery.
*I would like to have regular reviews as I find it hard to find time to sort out appointments myself.
*Basically it's getting used to it yourself, and getting the position right.
*At the moment things are fine but ongoing support is essential.
*It's enough to know that the support is there if it's needed.
*We are very happy with the ongoing support from school.
*I appreciate any support with regard to his positioning.
*It seems to be a case of trial and error, but once you feel you've got it right it would be good if someone would come out to check.

SECTION FOUR: ABOUT PROBLEMS AND SOLUTIONS

This section seeks to identify problems encountered and to derive benefit from the thoughtful and ingenious solutions that have been devised by families, users and therapists over the first year of use of Symmetrisleep.

4.1) What specific problems have you encountered at the early stages of use?

4.2) What solutions were tried in order to solve these problems?

4.3) Were the solutions tried successful?

The questionnaires were categorised as follows:

Those who identified that they had no problems with use of the system - 3
Those who identified problems which have been solved - 18
Those who identified problems, the solutions to which are still being sought - 8
Those whose problems have not been solved and who had given up - 2

Certain categories of solutions recurred to the extent that it is useful to identify numbers.

Solutions associated with temperature control - 13

Many individuals benefited from the retention of warmth by the overmantel, for those who felt too hot, the 'Lowzone' overmantle has been replaced with sheepskin combined with padded brackets. Adjustment of the weight of coverings had been necessary for some individuals.

Solutions associated with getting used to the system - 7

The solution to this problem lies in supporting the whole family to allow the individual sufficient time to adjust. The level of support and time required has been found to be variable. In cases involving a long period of time, often divided into several attempts, a relaxed, 'freedom to fail' philosophy on the part of both parents and therapists is essential along with use of appropriate behavioural techniques.

Solutions associated with achieving an acceptable position - 11

To increase the chances of acceptance, it was found that positioning within the system needed to be close to the already established sleeping position at first. It was also found that the time taken to find a comfortable position was often recognised as being closely related to the amount of time taken for individuals to 'get used to it' and for parents to 'get the hang of it'.

In 3 instances parents mentioned that established breathing difficulties had to be taken into account. In a further 2 instances parents identified that reflux problems influenced use of the system.

SECTION FIVE: GENERAL COMMENTS AND THANKS

General comments were encouraged and the respondents were thanked for their time and co-operation in taking part in the survey with the anticipated benefits to other users being described.

When asked for general comments about the system respondents gave a variety of answers, not always strictly associated with the system. The responses have been categorised as:

Very positive - 6
Positive - 16
Neutral - 6
negative - 1
very negative - 2

Examples of comments

*Don't worry or panic is you don't get it right first, second or third time round. It does not matter if you give up for a while and try again when you are ready.
*It is fantastic. It does everything we were trying to do for him when he was 3 or 4 years old.
*Getting set up was hard at first but once we got used to it we were fine.
*We are happy with it. I know what I am doing because I know how my child needs to be.
*I simply did not like it.
*It is a really good idea that seems to work.
*He is happy in it and it is doing him good so we are all happy with it.
*It is excellent.
*It is worth persevering. I wish we had had it years ago.
*It is a load of rubbish.
*It is the best thing we have ever had. It enables her to get a good nights sleep in a good position.
*It is really user friendly and was so easy to take on holiday.
*If it will stop him needing surgery it is fantastic. I can see for myself that his hips and spine are straighter.
*Once the (heat) problem is sorted out it will be brilliant.
*It seems to have worked for her and it helps her to sleep better.

CONCLUSION

Families require training and support to provide this form of treatment but short-term results indicate benefits, even for those with established problems. It is considered that accurate therapeutic positioning at night offers an important opportunity to influence body shape and sleep patterns (Goldsmith, 1998b) which should be made routinely available to motor impaired individuals from a young age, or as a matter of urgency for those with late onset of disability.

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