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Association for Spina Bifida and Hydrocephalus/ASBAH 10p Nov/Dec 78

ASBAH Annual Report: New hope for shunting devices: One Child's Story: Management of Limbs: LIFT reports

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A view of open employment

READERS will know that, in order to encourage and assist employers to accept disabled persons, Disablement Resettlement Officers provide special facilities, arrange grants and subsidies from Government sources. In addition the Disabled Persons (Employment) Act of 1944 requires all employers of 20 or more workers to employ a quota of registered disabled people. The standard quota is at present three per cent of the total payroll and applies to all commercial and industrial firms, local and health authorities and nationalised industries. Where industries and occupations are thought to be unsuited to disabled people a special percentage may be agreed.

A research report evidences that amongst employers there is a lack of knowledge of these facilities and suggests that, although most employers give full and fair consideration for all vacancies, disabled people should be more fully utilised, especially being directed along a careers path in which disability will not be a limiting factor.

The report has been published by Queen Elizabeth's Foundation for the Disabled and gives the results of a research project by students of the London School of Economics into the position of disabled people in open employment.

The researchers found that, within the sample of employers considered, about 20% were employing 3% disabled persons, 15% employed fewer than 3% and had no exemption permit, 8% did not know whether they were exempt or not. The report suggests that the Department of Employment's figures of 38.7% of employers having 3% of disabled employees is untrue.

Employers thought that the 3% quota was unrealistic, were unaware of the nature of disablement or of the services available to employers. Trade Unions appear to give even less consideration to the formation of positive policies for disabled employees.

It would be valuable to have from readers who are in open employment comments on their experiences. There are many disabled people who do not want any protection, who find the quota system antagonises colleagues, and wish to be employed, not as special cases, but in fair competition for work which is within their physical and intellectual abilities. Others will wish to be protected in open employment, including enforcement of the quota, despite the segregation which results from preferential treatment.

Access to further education, training, employment and integrated leisure activities on equal terms with the able bodied might satisfy the disabled person who is able to compete, but others will need protection in sheltered occupation and accommodation where they are given encouragement and opportunity to be the best that each can be. There is evidence to prove that the cost involved is a great deal less than the benefits which accrue.

Cover Story

FATHER Christmas speeding on his way in a superfast flying wheelchair—one way of using the Mobility Allowance perhaps?

This delightful cartoon is a Christmas present from GUS who drew it especially for LINK.

LINK: The last date for material for Jan/Feb LINK is December 1. *Write to Mrs Susan Gearing, Editor, LINK, ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ.*

The yearly subscription for LINK (UK) is £1.15, which covers the cost of postage. Views expressed in LINK are not necessarily those of ASBAH. While every care is taken to ensure the accuracy of information published in LINK the publishers can accept no liability.

A SURPRISE cheque for £400 for ASBAH's research programme was presented to Sir George Haynes, one of the Vice-Presidents, at the Annual Meeting of ASBAH in London in October. It was presented by Miss Druscilla Henley on behalf of Worcestershire Association.

Annual meeting hears call for higher income

SIR George Haynes, when closing the afternoon's proceedings, summed up the changing nature of ASBAH's work in a succinct and memorable way with a quote from Pascal:

"The centre is everywhere, but the circumference is nowhere".

ASBAH professionalism has a price

Sir George Haynes, CBE, one of ASBAH's Vice-Presidents, who chaired the afternoon session of the ASBAH Annual Meeting, held at the Middlesex Hospital, London in October, congratulated the Association on becoming much more professional during the year.

A number of new professional appointments had been made at national office, and locally (social workers and field officers), and as a result, he said, ASBAH was now continuing to grow as a strong, influential body.

It was ready and able to help its members, particularly the growing number of young people, and to initiate change for the better at national level.

However, as Sir George pointed out, this growth in strength and influence also meant an increase in expenditure, and in the next financial year ASBAH could expect to write cheques to the value of about £300,000, and income must increase accordingly to meet this.

Mr. R. M. Nichols, Honorary Treasurer, in presenting the Accounts said that last year ASBAH had managed to make ends meet mainly because of 'windfalls' such as legacies of over £50,000 and £40,000 from the Esther Rantzen TV Appeal.

He said it was not practical to continue relying on 'windfalls' and normal income must be raised to an entirely different level.

Local Associations were asked to remember the needs of National ASBAH, as well as their own requirements, when raising money. Mr. H. D. Macfarlane, ASBAH's Liaison Officer, said that there was a huge sum of money—about £150,000—held by Local Associations and representing about half their total annual income, which was not being used remuneratively. He was pleased that this situation was an improvement on the past. But he emphasised 'Most Local Associations continue to accumulate funds without knowing how they will be used'.

In closing the formal part of the Annual Meeting Sir George said how impressed he had been by the concern and hard work of ASBAH staff and gave great credit to the Chief Executive Officer, Miss Moyna Gilbertson for making sure that 'everything pointed in the right direction'.

- ASBAH's Chairman, Mr. O. J. Colman presented the Annual Report for 1978, and extra copies of the Report are available from National Office.

'You are always welcome at ASBAH'—Gwyn Fergie, Receptionist at ASBAH is presented to Her Royal Highness. Next to meet the Princess was Secretary Francis Durcan (centre).

ROYAL VISIT

ASBAH staff at National Office had a very special visitor in September—Her Royal Highness the Duchess of Gloucester, ASBAH's Patron, paid an informal visit to meet the staff at the Tavistock House offices in London.

The Princess talks with Miss Beverley Holland, Information Officer at ASBAH.

Hydrocephalus: In search of answers to shunt colonisation

ROGER Bayston, who is the ASBAH Research Fellow, spoke to the Annual Meeting about his work, based at the Sheffield Children's Hospital, into the prevention of shunt colonisation (the 'taking over' of shunts by foreign bodies).

He expressed his gratitude to ASBAH and its supporters for funding his work since 1974. His Research Fellowship began in 1976 and runs for three years.

Mr. Bayston said that he first became interested in the use of cerebral spinal fluid shunts (CSF shunts) in 1970 at a time when the field was one of total confusion— "No one had done any work of note to determine what the actual problems were, but almost everyone had solutions".

He decided to start from scratch disbelieving all that had gone before.

Opinion varied as to where the bacteria that caused the colonisation came from, and the air in the operating theatre, the surgeon's fingers, the nurses' noses had all been incriminated.

He was able to show, for the first time, that the bacteria came from the patient himself, arising on the skin, and that they always (in his experience) got into the shunt at operation.

He explained that diagnosis itself can cause problems because children with colonised shunts had symptoms which can point away from the correct diagnosis to illnesses such as influenza, or rheumatic fever. As a result children with unrecognised shunt colonisation were not treated, and some shunts were removed only to find that they were not colonised after all.

"To deal with this we have developed a blood antibody test which can detect evidence of shunt colonisation even before the symptoms appear. We have used this to screen all children having operations involving a shunt, and we have detected several cases of shunt colonisation, but all of these have been early cases.

"Serious complications, such as kidney involvement (nephritis), only occur in those children where the diagnosis is not made until months or years after the operation, and we have not seen any of these cases since we began the screening programme.

"The usual method of treatment for a colonised shunt is surgical removal, and this usually means another operation later, to insert a new shunt. No one is happy with this situation, but the alternative was the use of antibiotics which almost always failed.

"However, new antibiotics are now available which work differently from the older ones, and we have used them to treat shunt colonisation successfully in about ten cases. There have also been about six cases where this treatment failed but it seems that the criteria for success are early and accurate diagnosis and the correct use of modern antibiotics."

Mr. Bayston felt that in suitable cases it may be possible to use antibiotics instead of surgery, but emphasised that the study is in its early stages.

He then concentrated his efforts on preventing colonisation at the operating stage, using various methods, but to no avail.

He experimented with altering the silicone rubber from which shunts are made, by mixing antibiotic substances in at early stages of production. Although he was told by the manufacturers that this would not work because the high temperatures of processing rubber would destroy the antibiotics, he persevered and found that rubber can be processed at lower temperatures which would not affect the antibiotics.

Further work showed that although a tough silicone rubber could be made it had only a short life span because it remained resistant to infection for only about two days.

"At this stage I formed a small working group consisting of Dr. Dervin, a biomedical engineer from Salford, Dr. Gilding, a materials scientist from Liverpool, and myself. We felt strongly that a great deal of money was spent on foreign shunts when equally good ones could, perhaps, be made here.

"Dr. Dervin is developing a new type of valve which is very promising and which we hope will eventually be made in this country.

"We also looked at new materials from which to make shunts, and we are now studying the use of a type of material which is tougher than silicone rubber, is less likely to block, and is easier to make resistant to bacteria. We hope to be able to produce prototype shunts based on the new valve, and made from new materials, which do not deteriorate and which are resistant to colonisation.

"However, one must remember the tale of the tortoise and the hare, We have, perhaps, progressed too slowly for some, but if, for example, we had gone ahead and made shunts from the antibacterial silicone rubber without first conducting a detailed study of it, we would now perhaps be regretting it—and we may not have thought of using new materials instead.

We now have to conduct detailed tests on our materials to make doubly sure that they will work. At the moment it seems that we may soon be in a position not only to prevent shunt colonisation but to use antibacterial shunts in those children suffering from meningitis who are also in the process of developing hydrocephalus.

"It would be foolish to use an ordinary shunt while the meningitis was still active, because it would become colonised. We could perhaps prevent this by using an antibacterial shunt, and the hydrocephalus could be treated in its early stages.

"We have learned a great deal about the problems of shunt colonisation and how to deal with them, and I feel very strongly that this is directly due to your efforts and support."

THE Professor Zachary Fund was launched last year when Professor Zachary retired after serving as ASBAH's Chairman for eleven years.

He asked that the money received should be used to sponsor projects for young people - particularly projects suggested by the young people themselves; such things as travelling, furthering a particular interest or career, or buying musical instruments and sports equipment. Projects supported by the Fund can be quite large or very small.

The Fund would be glad to hear from any young people who need financial assistance with a special project. Write to National Office.

Alison (right) with American friends Donna and Mary.

Fund opens up way to youth rally in USA

THIS summer my husband, Ian, and I spent our holiday in the United States, and we received a grant from the Professor Zachary fund to attend the first National Youth Rally sponsored by the United Ostomy Association, and the International Association of Enterostomal Therapists, which was held at the University of Colorado, in Boulder, Colorado.

Ian and I were staying with friends in New York for the first part of our holiday, and we decided to hire a car and drive the 2000 miles to Colorado so that we could see something of the country.

At the University we were housed in student accommodation, and the programme began on the Sunday night with a party, where we first met the other participants. There were 200 delegates from all over the United States, whose ages ranged from 12 to about 30, as well as enterostomal therapists, doctors, parents and others.

The following morning the conference itself began with a panel on sex. This was quite interesting, although it was rather general.

In the afternoon there were concurrent workshops on Schools and Peers, Ileostomy and Skin Care, Colostomy, Urostomy, Continent Ileostomy, and a Parents' Workshop.

We attended the Urostomy workshop. Slides were shown on the importance of skin care.

That afternoon we attended another workshop, this time on spina bifida. The main discussion centred on alternatives to the urostomy, and the possibility of an 'undiversion' was also discussed.

The urologist explained that although the urostomy had at first appeared to be the ideal solution to the problems of incontinence connected with spina bifida, it had been found that many people who had had the operation subsequently suffered from kidney infections, and that the numbers suffering kidney failure had become unacceptably high. For this reason surgeons had looked for alternative systems of management.

There followed a discussion on the pros and cons of intermittent catheterisation. The urologist felt that this was a very good system, as it is simple, prevents infection and renal deterioration, and maintains continence, but I have heard other doctors who have misgivings about it as an alternative to the urostomy.

The artificial sphincter was mentioned but there is a 40 per cent complication rate at present, which is very high.

Many people were interested in the possibility of an 'undiversion' operation, after which it would be necessary to have an artificial sphincter, or use intermittent catheterisation.

It was generally felt however, that not enough of these operations have been done as yet to assess how successful they are likely to be. The bladder pacemaker was also briefly discussed, but it was considered to be unsatisfactory because of the rapid formation of scar tissue around the electrode.

In the evening we all went in buses to the summit of Flagstaff Mountain, which commanded a wonderful view of Boulder and the surrounding countryside, for a barbeque.

On the Tuesday morning there was a panel on sports.

That evening we all went out again, this time to a local ski lodge, where we had a meal.

We decided to go for a ride in a ski-lift. There was a marvellous view, and it was quite an experience, but I don't think I could ever do it again.

The following day the conference came to a close, with a medical panel which concentrated on a new advance for ileostomy patients, the continent ileostomy.

All in all it was a most enjoyable and exhilarating experience, and although the lectures were very informative the most enjoyable part, I think, was meeting all the people. We had many invitations to various places, and in fact we did visit one of the girls with spina bifida, who lived in Chicago.

ALISON DAVIS,

Teresa's the bridesmaid

IT'S the dream of most little girls to be a bridesmaid, and it came true for six-year-old Teresa Morley, who has spina bifida and is a member of Nottingham and District Association.

Teresa who lives at Mapperley, Nottingham is pictured at a wedding this Summer.

Photo: Nu-Style and Martin Allen.

■ ■ ■

FROM bridesmaid to bride . . . Mrs. Betty Wardale, 53, insisted on walking down the aisle at her wedding, although at times she does use a wheelchair. She was married at Nestor Grove Methodist Church, Hull earlier this year, and she and her husband are planning to join other members of Hull and District Association on a trip to Holland next May.

■ ■ ■

Congratulations to 11-year-old William Bidmead of Wrexham who recently passed his cycling proficiency test on his specially adapted, hand-cranked tricycle. He was the first handicapped child to do this in the Wrexham area. William took his lessons and test along with the other children at the local primary school he attends.

Sharon gets bumper post

A BUMPER bundle of mail for 12-year-old Sharon Neild - in fact, ten bags of it. And all because her mother, Mrs. Dorothy Neild, wrote to the Sunday Mirror saying that Sharon, who has spina bifida and is confined to a wheelchair, always longed for the postman to bring her something.

Several thousands of Sunday Mirror readers quickly put pen to paper.

Below, Sharon Neild, at home in Pennart, near Llangrannog, West Wales, with postman David Morris and some of the thousands of letters and cards.

Photo: Western Mail, Cardiff.

One Child's Story

THIS is the third and final chapter in the William Bee story - a story which has seen Will, who has spina bifida, grow up and win a place for himself at university. Will's story is, in fact, a family's story: a collective effort which enabled him to triumph over his handicap. The first two chapters showed how, in practical matters, necessity had truly been the mother of invention. In this article, Will's father, Mr. Roland Bee, sums up and concludes with one piece of unequivocal advice to other parents . . . PERSIST.

Will, himself, adds his own footnote.

MY PHILOSOPHY about bringing up children is that on the whole they turn out pretty well in spite of the mistakes their parents and teachers make. It is, in some ways consoling, but it also carries the warning that the young man or woman will be conscious mostly of his mentor's faults.

I stress this because, necessarily, this brief account is mainly about our successes. No two families are alike, and children with a physical handicap also vary in the extent of their disability, so that it would not be possible to say, "Do as we did and all will be well".

William has done well so far. At 15 he achieved nine "O" level passes, including a grade one CSE in metalwork, and was accepted for university after his "A" levels. He allocated 1977 for the latest orthopaedic operation, and took up his studies again in October.

We've never met a paediatrician or a physio-therapist, have had one call from a health visitor, and saw a social worker in action only when our Rowntree Trust application was checked.

It is our belief that had we sat back and let things take their course Will would have started at the special school shuffling on his bottom as did his contemporaries, would have stayed there till he was 16 or so, and left with a few "O" levels, helped by a nearby grammar school.

He would probably have been under-educated, frustrated, and perhaps embittered. He may well have caught up with his education later, but his character must have been very different.

Defects in health and social services.

We are convinced that in general (although one reads of exceptions) the services available to families of handicapped children are adequate only for their physical care and are not equipped to help the child develop as a whole person.

We have found the people in the health services unaware of, and therefore unconcerned about, the problems of caring for such a child at home. We found that the special school needed prompting to notice the problems of a bright child and the comprehensive school had to be prodded from time to time into coping with the difficulties of a disabled child, even where these seemed obvious.

In fairness, it should be stressed that the teachers concerned were always co-operative once the difficulty had been pointed out. We understand that many health visitors and social workers are unable to help with the practical problems of families with disabled children because they lack the relevant experience.

The purpose of these articles is not to criticise or change "the system". In the past few decades there has been an enormous increase in the survival rate of children with physical handicaps and of people disabled as adults. Much has been achieved in changing public attitudes to the disabled, but it would be unrealistic to expect parallel changes in deeply entrenched professions and institutions in so short a time.

We are convinced that parents can, and indeed must, contribute a great deal to the development of their children and we hope that William's story will give some of them more confidence in doing this. In the long run "the system" must be changed, we believe, in the direction of accepting and stimulating the parental contribution, but in the short run we must make the best of what is available.

Simple aids are better

All the devices I have described are extremely simple, made from scrap with help where necessary from local craftsmen. In these technological days people jump too readily to the complicated solution - sometimes very young children are given electric wheelchairs or stair-lifts, long before pushing or carrying them becomes a burden.

The Shasbah trolley has the merit of simplicity, but we are glad it was not available to us because we believe Will gained a lot from shuffling and crawling and had more freedom, and also because it might have reduced the incentive to get him walking.

In many cases the simpler solution is the better one - for example, our driving aid is cheaper and psychologically better than hand controls, and has the merit of exercising William's good leg.

Our aims - and hindsight

During Will's first few years we gradually developed a determination that he should be able to live a full

William Bee with the Batric chair which was one of several keys to his growing independence.

and independent adult life, and when it became clear that he was reasonably bright, this included a university degree as a target because it seemed probable that mental skills would give him more scope than physical ones. We didn't push him, beyond explaining this probability, but we put considerable effort into clearing the obstacles and trying to give him as wide a background as possible.

We've tried to make the best of circumstances, and in some key instances have been lucky with our timing. Looking back, we feel that boarding at the special school was good for him because, with one house mother looking after half a dozen children, they all had a good deal of ''healthy neglect'', whereas at home, however tough one tries to be, one helps a handicapped child too much.

With his foundation of boarding school and much time away in hospital (though we visited every day until he was 15) Will has become very poised and sociable and a keen observer of human behaviour.

The move to an ordinary school was necessary and timely, though we do not see this as a condemnation of the special school, and he gained enormously from mixing with ordinary children and from the greater mental stimulus.

The primary school could hardly have been in a worse building, Victorian, two storey, with worn stone stairs and horrible outside toilets. Fortunately Will's classes were in pre-fab extension buildings at ground level, and the staff co-operated well so that when necessary he could use his wheelchair, even with a leg in plaster. He was happy there and soon caught up with the rest.

The comprehensive school to which he transferred with the rest of his class was more modern but still multi-level. The staff and children accepted him well, and, without being over-protective, saw that he wasn't crushed in the rush of children and made some effort to bring him into the school games and other activities. The education authority paid a teacher to transport him to and from school - cheaper and less unreliable than a rural taxi - until he was old enough to drive himself there - for which the authority also contributed.

Will thoroughly enjoyed his schooling and made some good friendships, to which his Batric chair and car made a contribution. Indeed, he adjusted so well that in his final sixth form year I had to remind the staff fairly emphatically that his ''O'' levels had been taken with an operation looming up immediately afterwards, and that this had cost him half of his first sixth form term. This was necessary to ease the pressure of ''A'' level exams. The school reacted well, obtained for him an extension of examination time, and made appropriate comments on the university application forms.

Well equipped

William is a well adjusted young man. We talk about his disability freely, and watch and discuss television programmes on such questions. He should be well equipped to settle in happily at university and to look after himself.

Most children - disabled or not - are unsuited to academic life. Many children with a spina bifida suffer some brain damage, or have the problems of hydrocephalus, incontinence, and more serious physical difficulties than William.

It would be tragic if these articles seemed to make light of these more serious problems, or to suggest that our regime would be right for other people's children. But we do believe that parents have an enormous contribution to make to the development of handicapped children, that this is undervalued, and indeed that all too often parental confidence is undermined by the professionals concerned.

The fruits of experience

Perhaps it may be useful to summarise the fruits of our experience as a family. These are:

1 Try to understand your child's condition as fully as you can. Persist in reading and asking questions until you grasp what its all about, but then don't dwell on it and become addicted to medical dictionaries.

→

Continued from p. 9

2 Most of your medical contacts will be with hospitals and clinics, but your GP should receive reports from the hospital. Try to gain his confidence so that he can explain these to you, and can also help with the problems of home care of which the hospital may be unaware.

3 We (mostly Joan) visited Will every day when he was in hospital until he was 15. We felt from the first that as he must spend much time there we must do everything possible to make him feel secure. Daily visiting isn't practical for all families, but we do feel that it is very important for a child to know when he will be visited and that he be made as secure as possible when away from home.

4 Remember that it is normal for a young adult to leave the family home, and that the independence this gives is important to full maturity. Try to give your child as much independence as you can so that it becomes possible for him (or her to live away from home, even though there may be a continuing need for some outside help.

5 Many problems will arise in bringing up your child, similar to the ones described here. For some of these there will be no solution readily available. If you cannot find an answer - ask. Ask your GP, social worker, or health visitor - write to ASBAH or other charities concerned with the disabled - above all, persist. If you want to make a device such as I have described, and are unhandy, try to find a helpful neighbour or a model engineer who is interested, even your local garage, and again - persist.

6 We felt strongly that Will should not be an only child and have always been glad of the risk we took. Genetic counselling and pregnancy testing are now available to explain and reduce this risk. Whether or not there are other children, the family must to some extent revolve round the needs of a physically handicapped member, but we believe this should not be overdone. For example a child should be trained to help, if only in shelling peas; outings and holidays should be the best compromise between what all can enjoy and what is physically possible.

7 The Welfare State, with its leaflets, forms and bureaucrats helps most readily those best able to help themselves - the better educated, the more articulate and the confident. Find out what you are entitled to - whether nursing aids, attendance or mobility allowance, or whatever is appropriate. If your application is refused, enlist the help of social worker, health visitor or GP; if this fails try a local councillor, your local ASBAH group or write to ASBAH in London. The key word, again, is persist, if your need is genuine and you try hard enough there'll be someone willing to help, even though you may be no good at filling in forms or writing letters and aren't a good talker.

It is not possible to generalise from the experience of one family, but we hope that others may be able to profit from our experience.

We hope this may be so, and find ourselves on the one hand, urging parents to realise that there are many gaps in the health and social services that they can fill, and to have the confidence to do this; and on the other hand, to proceed carefully, to seek advice, and then to back their own judgement. This is a difficult path to travel, but has been well worth the effort for us.

THE END

At the end of this three-part series by the father— the son adds his own perspective.

William sums it up

THE continuing theme throughout my father's article has been my parents' attempts to ensure I was as independent as possible. However, the account shows that he was unaware of some of the limitations which their efforts placed on me.

We live in a rural area with an expensive and inadequate public transport system. From the age of 14 I had to travel considerable distances to visit most of my school friends and I was forced to rely on my parents for lifts there and back.

Money was also a problem as it was virtually impossible for me to obtain a Saturday job, and again I was totally dependent on the (perfectly adequate) pocket money given me by my parents.

Sanctions

By the age of 15–16 my friends were experimenting with under-age drinking and visiting X-certificate films, actions of which I knew my parents disapproved. However they were in a position to impose far more effective sanctions, through the money and the lifts they gave me, than most parents.

A perverse reaction of mine to this threat of sanctions was to refuse lifts rather than risk humiliation should they suddenly be withdrawn. I'm sure this slowed the development of many of my friendships, although, fortunately the arrival of my car largely resolved the problem.

Most disabled adolescents must be aware of the possibility of such restrictions being imposed by parents who disapprove of their behaviour. In flat urban areas it is possible that a good electric wheelchair could be almost as liberating as a car.

In some parts of my father's article the NHS has come in for some muted criticism. This is well justified but the service is still, in my opinion, a great success.

If my parents had been forced to pay for my treatment in any more obvious way than through the Inland Revenue I would have felt an enormous moral and financial debt to them. Nye Bevan's creation may have a few blemishes but it remains the greatest post-war British achievement.

My father's story closed 12 months ago as I was about to leave for university. My first year has been a huge success. My social life, hitherto restricted, has been full to the point of excess and I have made many good friends.

By consistent treatment and careful inspection my feet have been free from trouble and on seemingly miles of walking every day I'm as fit as I've ever been.

Despite all this I still managed to pass my first year exams.

My parents' aim of making me as independent as possible has succeeded more than any of us dared hope, whether I am mentally well adjusted is for others to judge.

A chance to sit up and take notice

SADLY, there are some children, handicapped both mentally and physically, who are unnecessarily condemned to a lifelong horizontal position.

As a result of lying on their backs with bent knees since birth, the weight of gravity and the pull of spastic muscles have caused the knees to drop down until the hips have gradually become dislocated. Once this has happened the child cannot bend at the hips for sitting and can only adopt the lying position.

At Clarefield Court Hospital, Maidenhead, two girls, aged eight and 15, were permanently bedridden because of this fixed frog posture of the legs. A simple chair was devised, however, in which they can now sit in an upright position. This gives them a greater chance of developing their full potential.

The child's legs are placed astride a foam roll* incorporated into a wooden frame. Foam cushions, 4'' thick, fully support her at the back and chest. There are padded wooden arm rests at the side.

Each girl was placed in this position for only a short time at first, to allow the heart to adjust to the extra demands made on it by the upright posture and also because head control was poor. This improved and the child could then begin to use her hands.

The younger of the two girls soon learned to hold a pencil and feed herself.

There may be other children who are similarly bedridden who might also benefit from a seat of this sort. Further information about the Clarefield chair can be obtained from Mrs. E. Heritage, 21 St. Margaret's Rd, Maidenhead, Berks SL6 5DZ. Diagrams of the chair are available from Jill Vernon, ASBAH Aids and Appliances Office.

* High density foam cylinders 15" diameter but 30" long are available from Price Bros. & Co. Ltd., Wellington, Somerset covered with waterproof material, or uncovered. They can be cut to the right size (15" long) with a bread knife.

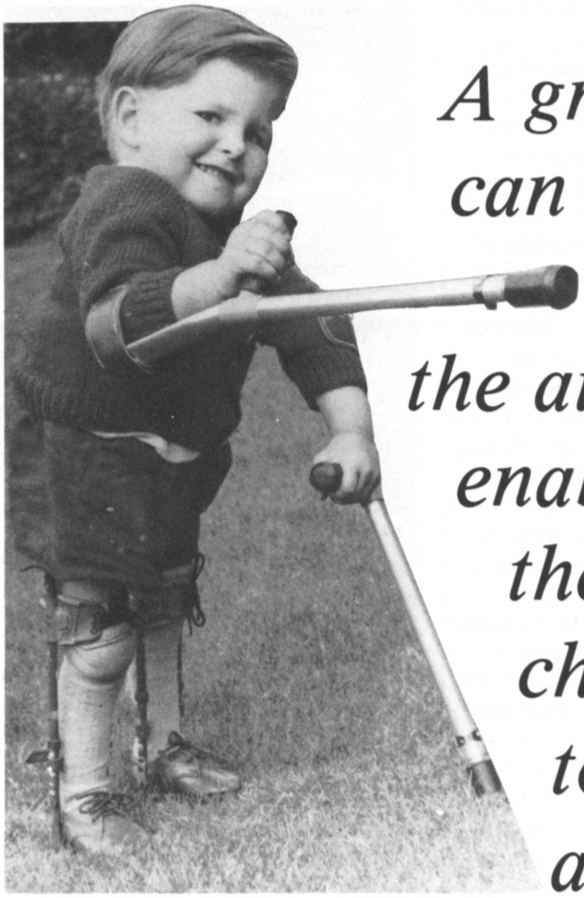
CORRECTION

HURSTWOOD TRICYCLES are available through Mr C J Wright. We apologise to Mr Wright for the statement in the last LINK.

The address for information on the trikes is: Mr. C. J. Wright, 13 Maiden Erlegh Ave., Bexley, Kent. Tel. 25 27207.

MANAGEMENT OF PARALYSED

"YOUR child's legs are paralysed - he will never walk." Some 30 years ago this used to be the verdict pronounced by doctors to many parents of spina bifida children. To-day a great deal can be done in the way of orthopaedic rehabilitation with the aim of enabling these children to stand and to walk.



A great deal can be done with the aim of enabling these children to stand and walk

The lower part of the spinal cord and the nerve roots are often malformed and not functioning in spina bifida children, giving rise to various types of paralyses of the legs and the bladder. According to the extent of the defect the paralysis can be complete or incomplete; the paralysis can be flaccid (muscles are limp) or - if some nerve cells are functioning below the lesion - it can be spastic (muscles are tight).

The management of the limbs varies according to the type of paralysis, but the common aim is to keep the legs in a position of function (standing, walking or sitting) and to prevent complications such as deformities, sores and fractures.

Deformities can be formed by three factors:

- **Postural Deformities.** Paralysed legs will rest in a position dictated by gravity: the hips will be bent and rolled outwards, the knees bent and the feet pointing downwards. Without treatment the legs may become stiff in such a position, making any form of functional rehabilitation difficult, if not impossible.

A great deal can be done to prevent postural deformities. Since the child cannot move the leg actively, we must move all the joints for him to keep them supple and mobile. Several times a day all the leg joints should be put through the normal range of movements; the doctor, the physiotherapist or the nurse should instruct the parents in these simple exercises which should be started soon after birth and if carried out regularly will prevent most postural deformities.

- **Muscle imbalance deformities.** If paralysis is incomplete one muscle group may be working normally, whilst another group is so weak that it cannot oppose the strong group which therefore tends to pull the joint into a deformed position.

Repeated passive movements may go a long way to prevent a fixed deformity, but a tendon transfer operation may be the more permanent answer to the problems of muscle inbalance. Spastic limbs are often more difficult to manage because the tight muscles do not yield as readily to passive stretching and exercises and therefore joint stiffness cannot always be prevented. Operations may therefore be necessary in order to lengthen or transfer tendons or release the tight capsule of a joint.

- **Congenital deformities** of the lower limbs are common, especially the club foot.

These are also treated by repeated gentle manipulations by parents, guided by the physiotherapist but quite often operative treatment is necessary.

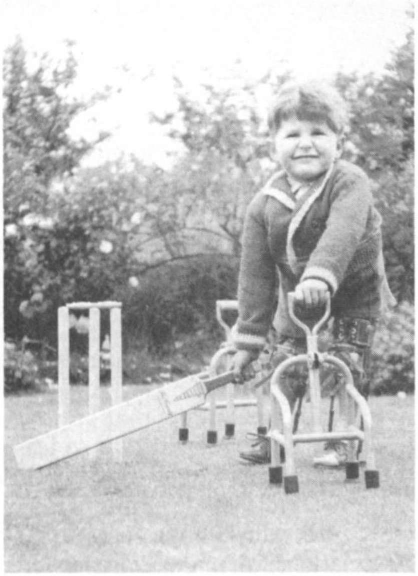
The main aim of orthopaedic rehabilitation is to enable a child to stand and to walk. This should be started at the age of fourteen months because it is normal for a child, at that age, to develop the balance of standing and some walking action.

If the legs can be put into the position of function, that is feet at right angles to the legs, knees and hips straight, it is a simple matter to fit an appliance which gives support to the weak legs and trunk. It is surprising how readily small children take to the walking appliance (nowadays called "orthosis"); they quickly learn to use the hands for support and balance and develop a rocking walking action (swivel gait); as they grow bigger they often develop a hinged gait at the hips (reciprocating gait) facilitated if some hip flexor action is present. In the older child hip and knee hinges are fitted to the orthosis to allow sitting.

In some centres the appliance preferred is a swivel walker, with platforms fitted under the shoes giving such stability that the upper limbs are not needed for support but are kept free for their proper function in play and work.

LIMBS . . .

by E. H. STRACH, FRCS(Eng), M.Ch.Orth.
Consultant Orthopaedic Surgeon, Liverpool



DAVID was three years old when the photographs on these pages were taken. He had complete leg paralysis but was obviously enjoying his ability to stand, walk and play with his orthosis and elbow crutches.

However, the swivel walker will not facilitate the more normal reciprocating gait and it will have to be removed for sitting.

A novel development in supporting paralysed limbs is that of using an inflatable appliance which is under trial at the present time.

Children vary greatly in their response to this type of rehabilitation. Once a child has mastered the walking action it will never be forgotten even if rehabilitation is interrupted for years for reasons beyond control. Older children find that the wheelchair gets them about much quicker. Nevertheless the ability to walk has given them a sense of achievement and increased their independence and self respect. Mobility also tends to prevent kidney complications, sores and fractures.

Sores are caused by prolonged pressure on skin which is devoid of sensation. If there is a bony prominence under the skin, this area becomes more vulnerable. Avoiding pressure on such skin can be achieved by operative removal of the prominence. Pressure from without can be minimised by suitable ring pads, but especially by regular training to inspect vulnerable skin. Wheelchair training in this respect is most important especially for the older child; regular press ups in the wheelchair will prevent pressure sores on the buttocks.

Pressure

All too frequently the orthosis is removed at the first sign of a pressure sore although it may not be responsible for it. As a result of this the child sits more and exerts constant pressure on the sore and it will not heal. Identification of the cause of the pressure must be exact before any action is taken.

Fractures occur mostly without any obvious cause or injury and they often go unnoticed because no pain can be felt. As a rule the first sign of a fracture is swelling of the leg. It occurs particularly after any prolonged immobility especially after the removal of plaster because the immobility makes the bone structure thinner and more brittle.

Fortunately these fractures heal well and quickly and splints or plasters do not need to stay on for a prolonged period. Fractures are rarer in children who are active and use the walking appliance frequently.

Many older children develop self help, are able to look after themselves, put on the orthosis, dress and undress themselves with minimal outside help. Many can transfer from bed to chair or to the toilet or at least take an active part in such manoeuvres. Such independence is often achieved in special schools where any particular ability of a child is developed so that it can take an active part in adult life.

1979 - Year of the Child

1979 WILL be International Year of the Child, and ASBAH is represented on two of the committees - one concerning 'The Child and his Environment' and the other on 'Children's Rights and Responsibilities'.

The British office for IYC is at 85 Whitehall, London SW1. Newsletters and further information about the activities planned will soon be available.

■ ■ ■

1981 will be International Year for the Disabled, and is being planned by the United Nations Organisation.

Alfred Morris, MP, Minister for the Disabled is Chairman of the World Planning Group which met to make initial plans in London in September this year.

Executive Committee

AS A result of the ballot at the Annual Meeting, Mr. R. Breeze, Mr. S. Mumford, and Mr. A. Twyford have joined ASBAH's Executive Committee.

Mr. D. M. Forrest, FRCS, Mr. B. Henley and Mr. T. Robinson, B.SOC.SC., have been re-elected.

HOLES IN THE WELFARE STATE

by Maureen Oswin, published by Bedford Square Press. Price £5.50 hardbound, £2.95 paperback. Available through bookshops or by post (£5.90 hardbound, £3.25 paperback) from Macdonald & Evans Distribution Services Ltd, Estover Road, Plymouth PL6 7PZ.

ALTHOUGH services for the handicapped have definitely improved in the last ten years, there are still distressing gaps and inadequacies in the way in which help and support is given to the handicapped and their families.

The author, who specialised in the care of handicapped children and adults for over 20 years, has tried to illustrate what life is like for a few of the people behind the figure of more than one million handicapped in this country.

It is a valuable book for professionals and non-professionals because it presents the facts—depressing though they tend to be—and it presents a powerful case for urgent reforms—an increase in specialist hostels and accommodation and counselling services—and an improvement in the understanding and kindness of professionals, relatives and the public.

SEX AND SPINA BIFIDA

by Bill Stewart. Illustrations by Liz McQuiston. Price £1 (or 75p to LIFT members), available from ASBAH.

THIS is the first of a series of informative books for LIFT members and all young people with spina bifida. Parents who feel unable to adequately advise on this subject will find this an invaluable book to give to their son and daughter.

Written and illustrated specifically with younger people in mind, it is an explicit, very factual and easy-to-read publication. It tackles with great sensitivity the subject of personal relationships, sex and coming to terms with one's maturing body and sexual needs.

It includes information on the way in which disability may affect relationships. The imaginative illustrations and diagrammatic information add tremendously to the appeal of the book.

In preparing the book contributions were made by Elizabeth M. Anderson, Ph.D, and Barbara Newman of ASBAH and others in the medical and teaching professions, and it was written in co-operation with the Committee on Sexual Problems of the disabled.

THE GARDEN AND THE HANDICAPPED CHILD

by Patricia Elliott B.Sc (Hort), Dip. Special Ed.
Published by Disabled Living Foundation. Price £2.50.

THIS highly readable book has been published in the belief that the garden has a considerable contribution to make in the development and enjoyment of the handicapped child.

It is written for all those responsible for the education and upbringing of handicapped children, and is liberally illustrated by Brenda Naylor and Elizabeth Watkins.

It is a book which adults who have any interest at all in plants will find difficult to put down and it would make a very acceptable Christmas present.

The book includes information on the practical aspects of gardening such as accessibility, correct tools, the care of various indoor and outdoor plants.

The educational value of gardening is also demonstrated, with chapters on the history of plants and gardens, plant names, how plants respond to different climates.

There is advice on how to lay out gardens and measure the growth rate of plants. There are even cookery recipes, and sections on drying and preserving flowers and making decorations using dried flowers.

The final sections is a practical guide to anyone considering gardening as part or full-time employment, with details of further education and training and where employment is to be found.

The book is available from the Disabled Living Foundation, 346 Kensington High St, London W14 8NS.

BEVERLEY HOLLAND
ASBAH Information Officer

LETTER

More publicity needed

WITH great interest I read Mrs Phillips' letter about the lack of information on hydrocephalus (LINK July/Aug).

My son is 13, and I've been asked over and over again 'What is hydrocephalus?' My son can't sit, talk or walk. He is mentally retarded and in nappies. He's as tall as me and has to be carried, by myself mainly, everywhere.

It's with great regret that I also wish he'd been spina bifida. At least those children have their intelligence.

Please don't let Mrs Phillips' letter be in vain. I hope all Associations will make hydrocephalus clearly understood, and as much as spina bifida. Like Mrs Phillips I think the public response would double. A poster here and there with a child's head 'enlarged' could get the message over.

A heartfelt thank you to our local ASBAH who are a tremendous help.

MRS RUTH HUMBER,
St Clements, Jersey.

Holiday weekend

A WEEKEND'S holiday in the late Summer at Pontins proved such a success that Worcestershire Association wrote to LINK.

Pontins at Prestatyn was the chosen spot for the weekend and a party of 47—17 handicapped members of Worcestershire Association with brothers and sisters and helpers arrived there one wet and windy Saturday in September.

'On arrival at Pontins Grand Hotel the manager and staff helped to "lift" wheelchair children to the lounge for tea or coffee.

Having settled in there was time for a quick swim.

The staff went out of their way to make the children comfortable.

The evening was spent watching a cabaret and enjoying a disco.

The weather changed dramatically the next day and the morning was spent happily in Rhyl in the sunshine. After a late lunch back at Pontins—'again the same superb food and service'—the party reluctantly had to pack before leaving by coach at 4 pm.

CLASSIFIED 'ADS'

Adverts for next LINK must be in by December 1 The address is: LINK Advertising, ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ.

Rate: £1.00 for up to 25 words. £2.00 for 25–40 words, £3.00 for 40–60 words. Please send remittance with your advert. You may like to pay for a whole year's advertising in one go.

HOLIDAY ACCOMMODATION

CAMBER SANDS: Well-equipped and adapted chalet (sleeps 6). Bookings taken from January by Mrs J. Wilson, 23 Sunnydale Gardens, London NW7. Tel: 01-959 2962.

SELSEY: Well-equipped specially designed, mobile home. 7-berth plus cot. Details (please send SAE) to: Mrs D. M. Driscoll, 3 Wandle Side, Wallington, Surrey, SM6 2DR.

WINTERTON-ON-SEA, Nr Gt Yarmouth: 6-berth chalet, indoor swimming pool, shop, play areas. Details: Mr R. Morris. Tel: High Wycombe 32184.

PRESTATYN: 6 berth caravan, accessible all amenities. Special reduced rates out of season. Details: Mrs E. Taplin, Colonial House, 63 Corporation Street, Manchester M4 3DT.

WITHERNSEA: Well-equipped 6-berth chalet at Golden Sands Chalet Park. Shop, licensed club, play areas, amusements on site. Details send SAE to: Mrs P. O'Callaghan, 14 Dyer Lane, Wheatley, Halifax. Tel: 0422-56402.

CHAPEL ST LEONARD'S, nr Skegness. Specially designed, well-equipped bungalow. Sleeps 8. Near safe beach. Bookings taken from March 1 from other Associations. Details: Mrs J. Brook, 11 Standiforth Road, Dalton, Huddersfield HD5 9HD. Tel: Hudd. 21776.

WANTED

Old fashioned clothes. Victorian up to 1940. Please contact me before giving away Granny's old clothes, especially nighties and blouses. Cash paid. Please tel: 01-658 0660.

SERVICES

THE DISTRICT Advertising Company of EMI Elstree Studios, Shenley Rd, Borehamwood, Herts. WD6 1JG, offer a special service to charities. They produce telephone, address and notebooks free of charge, for fetes, bazaars and other events; fund-raising charts, with pockets for donations, which also help recruit membership and promote your cause, and are displayed in public houses, restaurants, on factory noticeboards and other prominent places; programmes for fetes, donkey derbys, bazaars and football matches etc. Calendars and Diaries can also be obtained, all free of charge. For further information contact Mr J. A. Alter, at the above address or tel: 01-953 1600 ext. 171.

FOR SALE

Tee Shirts: White Cotton with Green Family symbol and words Support Spina Bifida. £1.60 each 22"-30" £1.85 small, medium, large, plus postage. State size. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks, for Bucks/East Berks. ASBAH.

Lord Snowdon Chairmobile electric chair. Unused. Will accept reasonable offer. Tel: Barry 736135.

Semi detached property, Fairbourne 65 Holiday Village. Porch, lounge/diner, kitchen, bathroom, sep. WC, 2 beds. R.V. £111. Price £10,000 including contents. E. Bennett, Owen, Estate Agent, Dolgellau, Gwynedd. Tel: Dolgellau 422789, or Barmouth 280272, or Harlech 540.

FOR SALE continued

Surplus: We have a number of Thistle Trikes available. For details contact Mr D. Greasley, 2 Waddelow Road, Waterbeach, Cambs. Treasurer, East Anglian ASBAH.

ASBAH booklets etc . . .

Your Child with Spina Bifida, by J. Lorber, MD, FRCP	25p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP	20p
The Nursery Years, by S. Haskell, MA, Ph.D, and M. E. Paul, Dip.Ph.H	15p
Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH	30p
The Care of an Ileal Conduit and Urinary Appliances, by E. Durham Smith, MD, MS, FRACS, FACS, and others	15p
Clothing for the Spina Bifida Child, by Barbara Webster, SRN, RSCN	15p
Aids and Equipment	60p
Sex and Spina Bifida by Bill Stewart	£1
(75p to LIFT members).	
Information leaflets	100 for £1.30

All available from ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 9p per booklet.

Scottish Spina Bifida Association Booklets

Growing Up with Spina Bifida, by O. R. Nettles, MCSP, ONC	20p

Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

FUND RAISING AND PUBLICITY MATERIAL

Posters

Best Foot Forward 20 × 30 in.	**10p each**
Best Foot Forward 15 × 10 in.	**10 for 40p**
For local publicity 15 × 10 in.	**10 for 40p**
Car Stickers	**5p each**
Cards for Notice Boards	**10 for 10p**
Plastic Lapel Badges	**3p each**

All available from Appeals Dept.—postage extra.

The Appeals Dept. carries a range of fund-raising items, i.e. pens, balloons, calendars, matches, tabards, car stickers. Send for list and order form.

Flag Day equipment can be obtained direct from: Angal, 48a Holmbush Rd, London SW15 3LE (01-788 5464).

Local Association changes

THE following changes of Honorary Secretaries have taken place since the last LINK. A full list of Associations will appear in the next issue on page 16.

HAMPSHIRE SOUTH
Mrs Jean Smith,
9 Albatross Walk,
Peel Common,
Gosport,
Hants.

HUDDERSFIELD
Mr P. Griffiths,
67 Dunford Rd,
Holmfirth,
Huddersfield.

PRESTON
Mrs A. Sherriff,
14 Nelson Crescent,
Lea, Preston,
Lancs. PR2 1TT.
Tel: Preston (0772) 720379

Why LIFT must have regional bases

LIFT - young ASBAH - has been in existence for just over a year, and so far it has issued three newsletters and organised three Independence Weeks.

If LIFT is to expand and involve more young people disabled by spina bifida and hydrocephalus it is important that regional groups are established. Several groups are already in existence.

LIFT on a regional basis means that many more members can take an active part in their organisation, by attending meetings to discuss topics of particular interest, or by taking part in other activities.

Regional groups can act as information centres enabling members to find out what services, social activities and clubs are available locally.

If you would like to take part in a local group perhaps you would let me know.

Jan Tomlinson,
National Officer, LIFT

Spreading the word on independence

BARBARA Newman and Jill Vernon, ASBAH National Officers gave a paper at the recent European Conference of Rehabilitation International, held at Brighton in conjunction with the NAIDEX '78 Exhibition.

The paper, entitled, 'Development of Independent Daily Living Skills and General Maturing of Severely Handicapped Teenagers' pointed out that more and more children with spina bifida and hydrocephalus will be leaving school over the next five years. ASBAH was concerned that many parents were receiving little guidance on what to expect from their handicapped son or daughter, and teenagers themselves had little idea of how independent they could be away from the secure environment of home and school.

This prompted the pilot Independence Training Weeks, which proved so successful that a full programme for 1979 is now being prepared.

Barbara and Jill feel it was a very useful opportunity to explain ASBAH's work to a varied audience from this country and all over the world. It is hoped that this will lead to co-operation in providing more opportunities for young people.

Stephen, Gary and Stephanie during one of the Independence courses

Anne discovers value of training week

"In February I went on an Independence Course at Five Oaks in Ben Rhydding near Ilkley, Yorkshire. There were eight of us on the course - five girls and three boys.

"The first morning we had breakfast in bed, and then the staff and helpers watched us get ready and helped if any of us who really needed it. The whole point of the course was to see just how independent we were and to encourage and help members to become more independent.

"During the week we had various talks about hair-care, job prospects and lots of other things. We also washed clothes and cooked meals.

"I made lots of new friends during that week and I learned quite a lot as well.

"The staff at Five Oaks were all very nice and they were helpful.

"I had a go at archery which I found I liked very much even though I did get quite a few bruises!

"We went to a local college and we had our dinner there, and then we all went shopping. It was fun.

"I would recommend these Independence Weeks to everybody, so if you ever get the chance to go on one take it."

Anne Cochrane, York

EXPERIENCE with Independence Weeks has shown that a variety of staff are needed, and sufficient helpers are required to establish a one to one relationship with each course member.

If you are, for example, an occupational or physiotherapist, or just an interested volunteer, and would be willing to help for at least one week per year, Jan Tomlinson would be pleased to hear from you.

All helpers will be given a short preliminary training session.

IF YOU want to know what Independence Weeks are being organised next year, or if you want to know more about LIFT, write to:

Jan Tomlinson, LIFT, ASBAH,
Tavistock House North,
Tavistock Square
LONDON WC1H 2HJ