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Association for Spina Bifida and Hydrocephalus/ASBAH 10p July/Aug 78

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Spina bifida statistics

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Tel: 01-388 1382/5

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ASBAH has an experienced staff ready to help with any problems relating to those with spina bifida and hydrocephalus.

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Mrs S I Gearing

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Pages

THE LONG awaited Warnock Report has now been published and those of us who have managed to wade through the 400 odd pages have found it most readable and most interesting. For those with less stamina I am informed that a 'pocket' version selling at 75p, will soon be available. Whilst the cynics may find some of the earlier chapters on integration in ordinary schools 'where possible' too wide open, further reading will cheer them.

Should we not all reflect on the finding that one in five children will need some type of specialised education at some time in their career? There are many more handicaps than spina bifida and many are much more crippling.

Attention has been paid to the Special Schools, with particular reference to curriculum, standards of education and specialised teacher training for those working in the schools. It is also recommended that special schools should be junior and senior rather than all age.

A very important recommendation is that at each stage the handicapped child's parents should have a named person with whom to consult. Also important is the section on assessment of the child's needs by a multi-professional team starting before school or even nursery education. I personally was pleased to see the extent of 'possible' educational avenues suggested for the handicapped child. We all, I am sure, realise that although we might hope the children may be integrated into the normal school this is often neither possible or practical. The Warnock Report gives several alternatives.

Training, further education

The Report deals not only with school children but with training and further education of young handicapped people. Perhaps we might be forgiven for saying, or thinking, that 'we told you so' but how cheering to see reported so well many of the problems we may have met, and better, to see recommendations for improvement of facilities. The Report points out that many have preconceived ideas of employment for the handicapped and a great deal of detail has been given to the need for adequate career counselling and follow up education and training; the need for employers to be educated as well as employees; the suggestion that some disabled persons, who are fit enough to do so, should be trained as teachers for not only special but ordinary schools (close to my heart).

The most important thing I feel that has come from the Warnock Report is that the problems have been discussed fully and many points brought to light that otherwise are known to so few and those particularly involved. The Report will be read, discussed and hopefully acted upon by those concerned with the education of handicapped children and young people.

If you have read merely press reports of the Warnock Report, depending on your paper you will have varying views. I would urge you to see the report itself (or the potted version). The recommendations are not only sensible but practical.

FAITH M. SEWARD BA
ASBAH's Education and Training Sub Committee
Vice-Chairman and a head teacher

LINK: The last date for material for Sept/Oct LINK is August 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.

COVER STORY

Stephen Collett, aged 10, who has spina bifida, playing his part in the Leeds Schools Musical Association primary school concert recently. See Mrs Collett's letter (page 5). Photo: Yorkshire Post.

How North Wales set about spreading the word

A YEAR has passed since the Job Creation Project, which enabled the North Wales Association to employ two liaison officers, began its work. We hope that the Association has now become a recognised body throughout the counties of Clwyd and Gwynedd.

The question everyone asks, and we ask it of ourselves, is what have we achieved in this year? In some areas, we possibly haven't done as much as we would have liked to, but overall, we feel that the North Wales Association is now offering a unique service to its members and statutory bodies in the area.

For those of you who have never visited this part of the country, it will be hard for you to appreciate one of our greatest problems—the sheer vastness of the area. North Wales has a total population of just over a million, but the total area is something like 200 miles by 100 miles.

Great space

Fortunately, for us, most people live along the coast or in the industrial areas around Wrexham, but there are those who live a somewhat isolated existence in the rural communities. Within this great space, we know of 139 families, where there is a member with spina bifida and/or hydrocephalus and it is in trying to give these families a sense of "belonging" that we have made our greatest efforts.

This is where the monies provided by Job Creation Programme have been such a boon. Two liaison officers have been employed, one for each of the counties of Gwynedd and Clwyd. They have visited and made face-to-face contact with every one of our members.

Many families have found this extremely advantageous, as it has given them the opportunity to discuss their own personal problems and the work of the Association.

Difficulties have been sorted out concerning DHSS Allowances, incontinence equipment, wheelchairs, education etc. To supplement this occasional visiting, the liaison officers have also founded Parent Groups in six different areas, where speakers are invited and parents can discuss their mutual problems.

Our news letter 'Link-Up' has been the final back-up. This has provided local news and gossip as well as a Swop Shop and information on important national topics. We feel our journalistic efforts have improved with time and we know that parents greatly enjoy this form of contact. We also, of course, had the necessary Christmas parties and visits to the pantos.

The Association has been most fortunate in obtaining offices in Llandudno and parents know that they can ring and call, at any time. Likewise, representatives from statutory bodies are also welcome.

We frequently have visitors, as we have a resource centre, probably unique in North Wales. Information is available on a diverse range of subjects, including holidays, education and further education, employment, housing, DHSS allowances, other voluntary bodies, aids and appliances, and we have produced our own brochures on physiotherapy. And, if we don't know, we'll always find out!

We have felt that it is important for a voluntary body, such as ours, to foster and maintain good relationships with local bodies concerned with health, social services, education, employment etc. The advantages of this policy have been mutual and whilst aiding statutory bodies, we feel that a better service has been gained from them, for our members. It has also meant, that where any dispute has arisen, we have all been able to work together to solve the problem amicably, so avoiding the use of our "pressure group" muscle.

Fund raising

Spreading the word about spina bifida and hydrocephalus, amongst the general public has also taken up much of our time. Press releases and articles and public speaking engagements, have all helped towards this end, and have often succeeded in boosting fund raising too! Needless to say, fund raising has been one of our main tasks and we've held a very successful Sherry Evening and Spring Draw, with a Laura Ashley Fashion Show, yet to come!!

All in all, a most successful year. Let's hope that funds can be found to make sure that the work goes on.

JACQUI DÖLL,
Project Organiser
North Wales ASBAH.

News in brief

Orange Badges

THE ORANGE Badge scheme, designed to make parking easier for the disabled has been sadly abused, with the badges being far too freely available. However the scheme should be restored to something like its original purpose if local authorities use the new, DHSS recommended, medical certificate. This will have to be filled in by a doctor recommending the issue of a badge and should ensure a uniform approach to entitlement.

University hall

FROM September 1978 the University of Southampton will have a purpose-built hall of residence, capable of accommodating 20 disabled students. Clarkson House has ten study bedrooms on the ground floor which will be allocated to wheelchair users. More information is available in the university prospectus from the Academic Registrar, The University, Southampton, SO9 5NH.

Access

THE MUSEUM of London, the Tower of London, the Guildhall and St Paul's Cathedral become much more manageable if you read the new Access Guide to the City of London. The guide, published by the City of London Corporation and Disablement in the City is available from City of London Information Centre, St Paul's Churchyard, London EC4M 8BX, priced 3p.

AND STILL on the question of access, The Newcastle upon Tyne Council for the Disabled has recently published a new guide, "The Ins and Outs of Newcastle upon Tyne. It is available from the Council, MEA House, Ellison Place, Newcastle upon Tyne NE1 8XS, price 55p (inc. p&p).

Fares to Work

LOCAL Disablement Resettlement Officers should now be able to advise on the new Fares to Work Scheme, introduced by the Manpower Services Commission. The scheme, which is no longer means tested, is designed to give the registered disabled help with the cost of getting to and from work. Applicants should be unable to use public transport and incur extra travelling costs because of their disability. For the first time those employed in sheltered workshops may claim.

The maximum benefit is £25 a week. People receiving Mobility Allowance or Private Car Allowance may claim but their entitlement will be reduced accordingly.

Olwen Nettles book

OLWEN NETTLES, who many LINK readers will remember as a former Aids and Appliance officer of ASBAH, has written a new book containing much good advice for families. "Counselling Parents and Children with Handicaps" by Olwen Nettles, NCSP, ONC is £1.50 from A. G. Tappenden Print, 16 Parkfield Close, Gossips Green, Crawley, Sussex.

Horse Riding

THE WINGED Fellowship Trust and the Pony Riding for the Disabled Trust are organising week long horse riding courses for beginners and advanced riders at the Fellowship's centre in Essex. There will be full residential care. The beginners course is from 25 November to 2 December and the advance course from 2 December to 9 December. The cost is £65 for either week. Further information from Winged Fellowship Trust, 2nd Floor, 64/66 Oxford Street, London W1.

Hydrocephalus: Why always second place?

I HAVE BEEN a member of ASBAH for nearly six years, and have now joined NASBAH after moving from Sussex to Surrey. When I first joined I obtained a metal spina bifida badge, actually feeling proud to wear it. But absolutely no-one has ever recognised the initials SB and the number of people who have remarked, "I thought SB were the initials of your own name!"

Why couldn't they be more clearly recognisable so that anybody who notices the badge would know what it signifies? Perhaps a larger badge with the actual words on it, rather than just SB, would be better. It would cost more to buy, but in my opinion it would be worth it.

Disabilities

IT PUZZLES me that hydrocephalus is not mentioned or discussed nearly as much as spina bifida. It always seems to be second in line. Hydrocephalus alone can cause so much brain damage, which obviously triggers off more disabilities.

My son, Derren, who is almost seven now, developed hydrocephalus at the age of six months, following a critical case of meningitis. As he has grown older, one thing after another has occurred—a very bad squint in his left eye, fits, incontinence, he is unable to walk, and there are several other problems besides. He cannot say one complete word even now.

I realise that spina bifida is a severe disability alone, but a child who has hydrocephalus without the addition of spina bifida can suffer just as much in life. At meetings, discussions, even on TV and in magazines, it's always just spina bifida, and if hydrocephalus is mentioned, it is kept very brief.

I have, like a lot of other mums, quite frequently been asked, when mentioning that my son has hydrocephalus, "what's that?" and when I try to explain, they still are none the wiser. I honestly feel that it should be brought out into the open more, so people, that have never heard of it, will get a clearer picture of the handicap. I also feel it will stir up the attention of the public and could very well help fund raising etc.

One has only to look at the list of books available, printed on the last page of *LINK*, to see that from all on the list, only one is on hydrocephalus alone. I wonder what other members feel about this.

MRS GILLIAN PHILLIPS
(single parent)

Cover story

A VERY HAPPY TEN YEARS

STEPHEN and I were on the cover of LINK in the Summer edition 1970, and I thought it would be interesting for you to see him now. Although he has had several operations, on the whole it has been a very happy ten years, with so much joy and pride when a physical step is achieved.

He manages very well on one full length and one short caliper with his crutches, and only uses a wheelchair to cover any distance. He has joined the cubs, he loves music and has a good singing voice, being a member of the school choir.

At present, Stephen goes to a special school, but we are firm believers in integration and hope that he will be able to attend a specially adapted school near our bungalow.

We had a second son in 1974 after having the amniocentesis test. Fortunately all was well this time, and the two of them are great friends and very good for each other.

I know that Stephen enjoys his life. Indeed, he leads a fuller life than many non-handicapped children of his age.

VALERIE COLLETT
Leeds

Loneliness: poem of despair

Two years have passed since loneliness was thrust upon me,
As the visible days vanish into weeks I know my dreams of success are broken,
Now I only sit in my four-walled room looking through my window.
Once the future opened its arms to me,
But since loneliness found me hiding in the darkness
I am a man who is afraid of light.
How can I learn to mix with my friends again?
How can I share the pleasure of a conversation?
Why can I not find the answers to my questions?
I can only live in my memories, my prison is my loneliness,
And knowing he lives only with his memories,
A man may just as well die in his past.

Roger Edwards 1967

. . . how picture can change!

ROGER, who is 30 and a quadraplegic spastic, wrote this poem two years after leaving special school when he was finding it difficult to come to terms with long, empty days in contrast to the busy, active life at school.

He writes: "I left school and for two and a half years lived with my family. Then I moved to a county council home for the handicapped near Bridgend.

"The picture has certainly changed now. I was married in July 1976 and live in a council house not far from the home. I attend a work unit, run by the social services which is about a quarter of a mile from my home.

"The work which is done there is mainly 'contract' work. In my spare time I am treasurer of the local community association.

"At the time I wrote the poem I was trying to get things out of my system as I felt then there was no future worth anything. I had no friends and no interests.

"If at any time in the future I can help your group I would willingly offer my services. I have given several poetry readings and would be pleased to do one for your Association (travelling expenses only).

Roger Edwards' address is:
8 Maes Glas, Ynysawdre, Tondu,
Bridgend, Mid-Glamorgan CF32 9JZ.

Mini-bus wins big smiles

A GOOD reason to be happy—children of Worcestershire Local Association with the custom built mini-bus which was bought for them by Stourport Round Table.

In the middle of the picture is the Chairman of the Round Table, Mr Bob Hildebrandt (left) with Mr Brian Henley, Chairman of Worcestershire Association.

Photo: Kidderminster Times.

ASBAH needs photographs

NATIONAL ASBAH needs a series of good photographs and slides to inform people about the achievements and needs of those with spina bifida and hydrocephalus, equipment available etc. These would be invaluable for publicity and information, and local associations might well be able to help.

It might be worth approaching a local amateur camera club. Members are often looking for 'projects' for their photography and if they were encouraged to take an interest in a local ASBAH they might produce some very good work.

Please do give this suggestion a try, as there is a real need for some good standard photography which the Association can use.

Some money-making ideas

TWO mayors and mayoresses, Miss Wales and more than 300 people attended a sherry evening held by the North Wales Association, in Llandudno in April. A grand raffle was drawn during the evening and altogether £2,000 was raised for the Association's work in North Wales.

■ ■ ■

IN SUSSEX, a coffee morning held at Arundel Castle by kind permission of Sussex Association President, Lavinia Duchess of Norfolk, raised £400. The Duchess was presented with a bouquet by one of the children, and spent some time chatting to members and touring the stalls.

More than 300 people attended the coffee morning.

GRANADA TV Rental employees in Bedford went on a sponsored slim and raised nearly £1,000, which was divided between Bedford and District Association and the National Chest, Heart and Stroke Association. Between them the 100 slimmers lost eight cwt.

■ ■ ■

CUSTOMERS of the Wentworth pub, Bushbury, Wolverhampton have proved real friends of Cannock, Walsall and District local association. They got together and through sponsored walks, dances, raffles and the local tote raised £1,788 towards a holiday caravan at Rhyl. The association members themselves were also arranging a variety of fund-raising events this summer to raise about another £1,000 for the caravan.

■■■

IAN HOLDER has proved himself a devoted uncle to 4-year-old Ashley Cradle, and indeed to other spina bifida children in the Crawley and Horsham area of Sussex. He gave up a week of his holiday to go on a sponsored cycle ride from his home at Maplehurst, Sussex to Land's End and back.

He raised well over £150 to be used to buy special equipment for spina bifida children in the area. On the way he met other fund-raisers—a woman walking a donkey from Land's End to London and a team of postmen cycling from John o'Groats to Land's End.

Thumbs up from marathon pusher

THUMBS up from a cheerful Michael Hanney (15) shortly before setting off to push himself over a 26 mile course in six hours.

He was one of 20 boys from Lord Mayor Treloar College for the Handicapped in Alton, Hants, who took part in the sponsored wheelchair marathon to raise money for the Arthritis and Rheumatism Council.

As it happened Michael was right to look so happy, and the smile was still there when he completed the whole course in an amazing 5 hours 10 minutes 14 seconds. Michael who has spina bifida was one of six boys who covered the full 26 miles.

Another of the boys—also with spina bifida—15-year-old John Naude of Liverpool made a place for himself in the Guinness Book of Records (under Human Achievements) by finishing the round in only 4 hours 5 minutes. Lots of the younger boys managed 8, 10, 16 and even 20 miles, and as a result of this magnificent effort over £3,000 was raised.

Photo: Bristol Evening Post.

Lions give Tamsin tricycle

TAMSIN James, 6, of Cambourne in Cornwall received a very special gift from the local Lions Club—a hand-operated tricycle. It was bought as a result of an appeal by the Lions for Green Shield stamps. It was particularly appreciated by Tamsin who has spent a lot of time in hospital in the past year.

Young Michael Chapman of North East ASBAH handling a kart.

Michael Hanney

Val Doonican and Alison

Alison receives special gift

VAL Doonican with 15-year-old Alison De-Valle who is looking very pleased with her new electric wheelchair. It was presented to her by Val, Captain of the Golf Fanatics, who put on special competitions to raise money for these chairs. Alison is a pupil at Pear Tree House special school, Kirkham, Lancashire.

Photo: Evening Gazette, Blackpool.

Go-Karting is catching on

NORTH East ASBAH is putting a lot of energy into developing go-karting as a sport for its members.

Mr Coulson of the Association writes:

"After looking at sport and leisure facilities we decided that there was a need for more areas of competition between the physically handicapped and the able-bodied as family units or schools.

"Our first venture is a Karting Club with 100cc karts capable of speeds up to 30 mph with hand-operated accelerator and brake controls similar to invacars. We are members of the Northumberland Schools Karting Association and the RAC have amended their rules to allow disabled drivers to take part in competitions.

Workshop

"The sport is dangerous but no more so than for able-bodied and despite some spectacular spills we have had no spectacular injuries."

Mr Coulson also reports that an aim of the Association in the North East is to have a workshop employing their young people where the karts could be made. Later this might develop to produce a whole range of aids, leisure and sporting goods.

If you are interested in starting a Kart Club in your area, North East ASBAH will be pleased to help. Contact Mr M G Coulson, 69 Marondale Avenue, Walkerdene, Newcastle upon Tyne, NE6 4HJ.

One Child's St

WILLIAM Bee was born in 1958 with a quite serious spina bifida condition, but no hydrocephalus developed. Here in the first of three articles his father, Mr W. R. Bee, a chartered engineer by profession, explains how he and his wife, Joan, used nearly every scrap of their ingenuity—not to mention a good many scraps of everyday material—in getting William mobile; in coping with his education and many other problems. This is one family's own story. Other families will have children with problems which are different from, and more serious than Will's. Mr Bee is not saying, 'Do as we did and all will be well,' but his article is testimony to family inventiveness and success in plugging some of the gaps in the health service. It should encourage others. The article is being serialised in three parts starting with this issue of *LINK*.

WHEN William was about four months old X-rays revealed that he had a dislocated hip, a condition which is sometimes linked with spina bifida. He spent the next five months with his legs bandaged to a tubular steel frame, a divaricator.

This spread his legs wide apart and prevented him bending so that we could only lay him down or hold him upright.

When he reached the age for sitting up he became fretful and restless so I made a little wooden chair with a saddle instead of a seat and a tray in front. This is shown in Fig. 1. It could stand on the floor, be strapped to a dining chair, or to a car seat, so that he became much more one of the family.

When his hip was declared safe, at about 10 months, his legs were like jelly and showed no sign of movement. He played happily sitting on the floor or shuffling about on his bottom.

The next stage in Will's development was to get him upright and walking. He learned to crawl and showed signs of wanting to pull himself up, but with both legs in full leg calipers it was clear he wouldn't make it. A half leg caliper was introduced for 20 minutes each day and Will quickly learned to pull himself upright. He went on to manage it while wearing both full leg calipers. Mr and Mrs Bee persistently sought advice which they could understand and in which they could have confidence concerning William's mobility, and . . .

The next suggestion was an 'Amesbury' walking aid, so we studied catalogues and ordered one. This proved to be a wooden frame with a saddle to support the child and a castor at each corner. Using this, we got Will to walk a little, and invented a game of 'hide sweet' in which the furniture was pushed to the sides of the room and lots of beakers were placed upside down, at levels he could reach, with 'Smarties' hidden under a few of them.

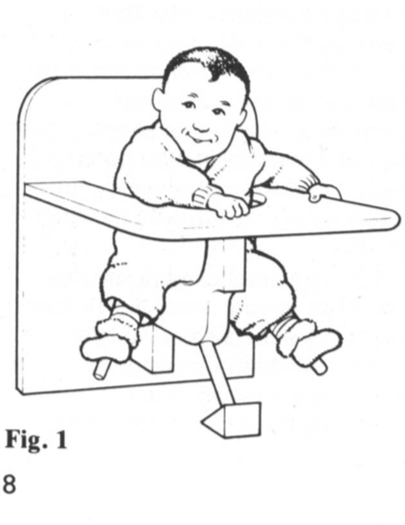

Fig. 1

He began to make progress, but it soon became clear that the 'Amesbury' was too big and clumsy for so small a child. The castors dug into the carpet and were hard to push, it was impossible for him to steer through a door and use it about the house, nor could he climb in or out of it himself.

When spring came, we tried it out of doors but the garden paths were rough and the castors got stuck. Joan tried carrying first Will, and then the aid across the road to a car park but this was little help.

Little incentive

We played 'hide sweet' every night after tea, but although he enjoyed it and pushed against the 'Amesbury' with great enthusiasm, there seemed no way he could use it alone, and as he could now crawl and shuffle quite well, there was little incentive for him to walk in his play, or to explore.

The next stage was to use the most flexible aid we could think of—myself. I learned to bend down, support Will under his armpits, and get him into a slow, rhythmic walk by moving slowly forward and using my knees to push his legs. This worked quite well and we fell into a routine of playing 'hide sweet' on weekday evenings and going for a 'walk' on Saturdays and Sundays.

The weekend walks soon began to last for half an hour or so which was as much as my back could stand, and this provided a spur to further thought.

We bought a standard 'push-along' truck. I removed the front wheels and replaced them with a castor. A normal child with one of these trucks raises the front wheels and bangs the truck around when he wants to turn. By converting Will's to a tricycle with a castoring front wheel we made it readily steerable so that he could use it for support at all times.

The truck at once replaced the 'Amesbury', and soon he was playing outside with it and using it for our weekend walks. By the time he was three he could walk quite well with it, and when he started school, at the age of 4½, he could run and was generally very nimble with the truck. Fig. 2 shows the truck, the handle of which has been lengthened to keep pace with his growth.

Like many children afflicted by spina bifida, Will has had many orthopaedic operations. These have straightened his feet and improved the condition of his legs. He now has a strong right leg with very limited movement and control of the foot. His left leg is almost

tory

WILLIAM BEE, AGED 19

useless and about 2″ shorter than the right, but the ironmongery on his legs was reduced to a half caliper on the left, which he still wears.

The immediate effect of each operation was, of course, that he had to learn to walk all over again and this must have prolonged his dependence on the truck. We started playing games in which he staggered increasing distances to me without any aid when he was about four and continued them for many years.

Walked best

I tried to introduce him to a walking stick but he would have nothing to do with it. He walked at first alone or with a parental hand, then used a hand only when crossing roads, and accepted a stick when he grew old enough to be ashamed of holding hands. He walked best when he was about nine or 10 and twice walked a couple of miles with a hand to hold.

His torso has developed out of all proportion to the strength of his legs so that although he can still (at 19) walk a fair distance, it is a very tiring process.

When he was at his most active he used to wear very quickly through the end of his caliper so that the pin broke off. After several experiments a friendly engineer obtained some oversize pins and brazed them on. We successfully drilled out the hole in the boot to fit. These pins completely solved the problem, and he still uses the larger pins, though sometimes a new boot is made with the small standard hole by mistake.

Shuffling and crawling

Having never walked really well, Will falls like a trained gymnast. I've often had to fend off shocked bystanders and let him pick himself up, quite unhurt. Even now, if he wants to switch on the TV, he rises from his chair, falls lightly to his fingertips and lurches forward to reach the knob in one smooth practised movement.

For many years, crawling remained part of his play-pattern. Joan made special trousers for him with leather patches on the knees and bottom, and my sister brought him a pair of 'Lederhosen' from Austria which were invaluable for the summer.

Shaped steel

We were always buying shoes for him because he had worn through the toes, so that when he was prescribed surgical boots it was necessary to protect the toes. I scrounged a bit of stainless steel, cut and bashed it to shape on a wooden last made to the outside of the boots and had the cuts brazed up to make external steel toecaps which screwed onto the soles of the boots. These worked well and by the time they became unnecessary I had made two or three sets and he'd worn a hole in the last one.

The surgeon always operated on Will at the end of the summer term, which was good educationally but meant him spending several summer holidays with his legs in plaster. We encouraged him to play outdoors, but soon found that concrete wears through plaster very quickly indeed. I solved this by making leather 'spats' to which I rivetted 'sledge runners' made from the half-round aluminium of old calipers which were bent to extend round the heel and protect the plaster by raising it from the ground.

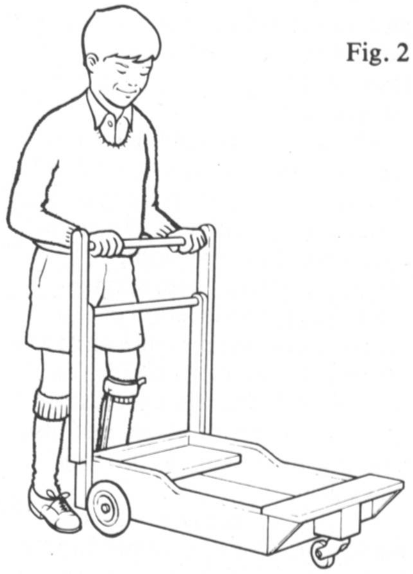

Fig. 2

They were a great success, indeed Will has recently recovered from another operation and we had to resurrect the spats because we live in a cottage which is inconvenient for a wheelchair. The spats were now too small, and as the shuffling was only on carpeted floors I replaced them with bits of plastic gutter fitted with wooden end-pieces and wooden 'runners'. These protected the plaster from the wheelchair footrests as well as the floor and saved much repairing of the plaster.

Will had to re-learn to walk yet again after the latest operation. His left leg drags across the floor and this very quickly wore away the sole of his new left boot at the toe. I used the same technique as for the steel toe caps to make protectors which are nailed to the sole but extend upwards round the welt.

I used a light gauge steel which wore very quickly and my friend very kindly welded up a heavier gauge one with a fillet of weld on the inside which is a great help—not only saving minor repairs to the toe, but protecting the welt from the damage it gets when climbing stairs.

Pressure sores

Will's feet have poor circulation and little sensation so that the right foot, on which he places all his weight, is very prone to pressure sores. In the early years they were treated in a number of ways. We disliked what were 'sticky practices'

continued over page

Continued from P. 9

and were delighted when a retired nurse demonstrated the old fashioned orthodox pressure sore treatment.*

This consists of rubbing round the sore with heavily soaped hands, then applying hydrogen peroxide, surgical spirit and talc. We often use a ring of animal wool, chiropody felt or foam sponge—according to the location of the sore—to ease the pressure and have learned the value of keeping the wound open because a premature scab leads to re-infection, and also of exposing the sore to fresh air and sunshine.

For many years now we have made a practice of rubbing and powdering Will's feet daily, and of regularly paring off hard skin, but always a sore-free period has led to over-confidence and a fresh sore, often only discovered on close inspection after he's complained of a pain in the groin.

However, with this treatment he's been kept sufficiently mobile to attend an ordinary school. When a sore has developed he's used a wheelchair at school but continued to climb stairs and walk to inaccessible places wearing slippers. The sores have only necessitated a day off occasionally, to give a long weekend with his feet up and open to the air all day.

Special slippers

Will has always needed slippers because his boots are so heavy, and to keep him mobile when he has a pressure sore. We managed to find carpet slippers with elastic inserts which adapted well to the shape of his feet, though, of course, we had to use one of each of two differently sized pairs.

As he grew, so we had to strengthen the right slipper to cope with his increasing weight. First we added elastic across the insteps of both slippers. Then we found that his right foot tended to push the side of the slipper over the sole so we strengthened this with a leather patch. As his weight increased this became less effective so we enlisted the aid of a village shoe repairer who now sews a piece of leather right across the toe, extends this under the sole, and anchors it with a stick-on sole.

Will's left slippers last indefinitely but he requires about four right ones a year, although we hope that the latest operation will ease the situation since the right foot is now flatter.

● Mr Bee mentions several 'do-it-yourself' aids in these articles. If anyone wants to see plans of these or would like more information please contact Jill Vernon, ASBAH's Aids and Appliance Officer. She should be able to advise on the suitability of these for individual children.

● Don't miss the next LINK for Part 2 of this story.

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* *Pressure sores: Although Mr Bee found this method very suitable and successful for his son, please do seek the advice of your hospital or GP before trying it.*

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How many babies are born with spina bifida and what happens to them?

CERTAIN people and organisations have repeatedly broadcast and publicised, in recent months, about the large number of babies born with spina bifida and what happens to them these days.

It is therefore, of interest to all—and our members especially—to get true, unbiased facts. These are available from the official statistics published by the Office of Population Censuses and Surveys, and by the Registrar General, for England and Wales. They put the matter in perspective.

The truth is that, fortunately, the number of babies born with spina bifida has been rapidly decreasing during the 1970s, and so have the number of deaths.

By 1976, for the first time, *less than 1,000* babies were born with spina bifida in England and Wales (live and stillbirths together!). In the early 1960s the figure was approaching 2,000.

Here are the most recent figures:

1974	1,185
1975	1,101
1976	880

The indications are that the figure for 1977 is even less, though we do not have official figures as yet.

There are many reasons for this major decline. There has been a considerable fall in the number of all births since the mid-60s. In 1966, 850,000 babies were born; by 1973 the numbers dropped to 676,000 and in 1976 to only 585,000.

Faster fall

There is some evidence that the birthrate in those families with increased risk of congenital malformation has dropped faster than in families with less risk. The influence of antenatal diagnosis played little part in this drop until about 1976. Up to then the national *birthrate* per 1,000 live *and* stillborn spina bifida was 1.8—little different from the 1960s. In 1976, however, the rate was only 1.5 per 1,000, and in Sheffield, where antenatal diagnosis has been practised for several years, the figure was 0.8 per 1,000. Antenatal diagnosis is more and more employed and this should lead to a further major drop throughout the country.

What happens to the babies born alive? In 1967–1969, when every baby in the London area was treated, Miss Spain found that only one-third were still alive at three years of age. This indicates the very serious outlook for the majority (mostly the severely affected) babies. Almost all the deaths occurred in the first year of life.

In the 1970s a selective treatment has been used on a progressively larger scale throughout the country, based on strict criteria, with the aim of treating all babies who have any reasonable chance of living, and living without gross handicaps. How has this affected national statistics?

In 1975 altogether 686 spina bifida persons died, of *all* ages. 584 died under one year of age, including 212 in the first week, who were, presumably, not salvagable whatever happened. The 584 deaths out of 1,101 born, was *a smaller proportion of deaths* than happened in the 1960s, when all were treated:

- *because* it was the worst affected who were not treated,
- *because* those with a better chance had better treatment,
- *because* the major centres were not under such immense pressure from numbers and from the amount of work imposed by the most severely affected babies.

Figures

By 1976, only 445 babies died under one year of age (164 during the first week) and in the first six months of 1977 there were only 208 deaths (102 in the first week). Altogether, in the first six months of 1977, 247 spina bifida persons of all ages died. This compares with 355 deaths in the first six months of 1975.

I think that these figures, all from totally unbiased official figures, are very encouraging and reassuring.

DR JOHN LORBER, MD, FRCP

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Motability—new scheme is now slipping into gear

SIX MONTHS ago the Secretary of State for DHSS, Mr David Ennals, made a statement in the House of Commons announcing the formation of a new organisation, Motability, to allow recipients of the Mobility Allowance to use this money in the best way possible to attain personal, independent mobility.

It is hoped that the first cars will be issued through Motability in July, 1978, but even now as this article goes to press, there are still details to be sorted out, and alterations to the scheme may be necessary.

What is Motability?

Motability is a charity and a company limited by guarantee. The Chairman is Lord Goodman, and there will be a number of paid staff based at Motability's headquarters in London.

Who will benefit?

Everyone receiving the Mobility Allowance will be eligible to use Motability's services, no distinction being made between the disabled driver and the disabled passenger. DHSS will send out a general leaflet explaining Motability to all those who are eligible, and later on you will be sent a further leaflet enclosing an application form.

How will it work?

You will agree to let DHSS pay over your Mobility Allowance to Motability for a fixed period (probably four years) and, in exchange, you will get a car on lease. This means that at the end of this period you will have to hand the car back to Motability, but then of course you can apply for another lease on a new car.

Maintenance costs will be included in the lease to ensure that the car is in good condition at the end of the period. If you choose the cheapest car—a Mini—costs such as insurance, road fund tax and petrol will be the only extra expenses. If you choose a more expensive car you will have to pay an extra lump sum at the beginning.

Who pays for conversions?

In most cases the disabled person will arrange extras such as an automatic gearbox or hand controls, and will pay for these himself. Motability will give advice about the best conversions to choose, and in cases of special need, help may also be available towards the extra costs.

Can I buy a car through Motability?

The first priority is to get the leasing scheme going. However, Motability is also looking at the possibility of a hire purchase scheme, although this is more complicated and will not be operational for some time.

Phasing in

Obviously it is impossible to organise the 40,000 or so cars that may be needed all at once, and so a phasing scheme must be used. Motability has decided to start with applications from young adults, and then work upwards towards retirement age, and afterwards consider applications from families with disabled children. Special priority will be given to those who need a car for their employment or to attend an approved training scheme, and these applications will be handled by the local Disablement Resettlement Officer.

The different groups will be phased in as quickly as possible, and hopefully no-one should have more than a couple of years to wait.

What should I do to apply?

Nothing! PLEASE WAIT! You will get a leaflet explaining the scheme, and an application form when your age group is eligible. If you write to Motability before this, it will only slow down the whole scheme.

(Thanks are due to Dr Adrian V. Stokes for permission to edit his article from the Disabled Drivers Motor Club magazine.)

ASBAH WORKING PARTY

ASBAH have set up a working party to look at all aspects of mobility, and in particular the problems of young adults with spina bifida and hydrocephalus. If you need advice on Mobility problems, contact Jill Vernon at the National Office.

WHOSE BENEFIT?

New study exposes tangled web

WHOSE BENEFIT? is a report produced by The Economist Intelligence Unit for the Disablement Income Group following a study, in great depth, of the United Kingdom welfare benefits system as it affects people with handicaps or disabilities.

The evocative roulette wheel on the front of the report illustrates the content which is not a guide but rather an exposé of a system of support which has become so complex that even the most conscientious of those charged with the task of giving advice and administering the benefits are failing in their service.

The background legislation and principles behind our system of cash benefits and services are examined as well as the resulting variety of organisations, criteria for assessment and problems of administration.

It is said that a handicapped person's social security provision might involve two to two dozen sources and applications, with the onus on those with least resources. The possibility of having to deal with claims for other benefits than the one for which the applicant first asked is avoided on the 'if they don't ask, don't tell them basis'.

The effect of each new benefit or service announced may not be to add to the income of those who qualify for it, but merely to change the label of part of that already received, while adding to the complexity of the choices which are presented.

There is an assessment of the costs involved and of the effects on all concerned and in conclusion the authors of the book suggest an independent inquiry into the entire subject of benefits with a view to complete restructuring of the system since further tinkering will only create more anomalies.

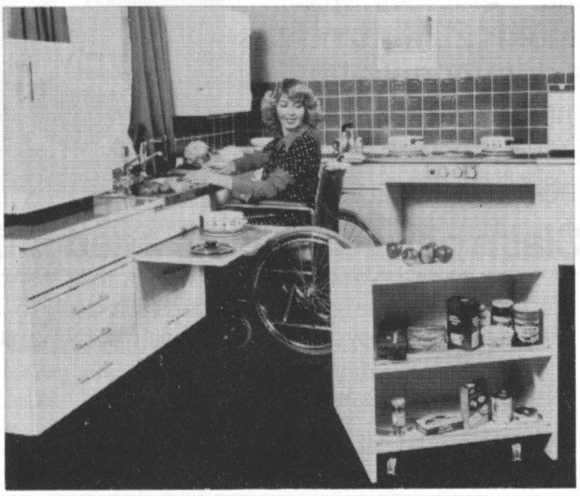
The book is available in a hardback edition at a specially reduced price of £3 to disabled people and charitable organisations only from The Publications Department, The Economist Intelligence Unit Limited, Spencer House, 27 St James's Place, London SW1A 1NT.

Children's book on spina bifida

Janet at School, by Paul White. This is the latest of a series of four books for children about different disabilities. This takes a look at Janet, a young girl with spina bifida. It shows how Janet, and also her friends and family have to learn to live with her handicap. It is written simply and clearly and the colour photographs by Jeremy Finlay are very appealing. Adam and Charles Black. Price £1.95.

- Paul White has kindly donated some of the royalties from this book to ASBAH.

Kitchens for the disabled.



Physical disability can severely limit a person's independence, especially in their own kitchen. To help overcome the problems, Moores in consultation with the country's leading specialists, developed a purpose designed range of kitchen units.

Flexibility is the key to the system. Flexibility in work top height, storage space and layout to help the disabled really make the most of their kitchen. Other features include easy access lower storage units, pull out midheight work tops, specially designed hob units, easy to open drawers and push release catches on doors.

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Dorchester Ball sets new record

WE CAN report with pleasure that our Annual Dorchester Ball was the most successful we have held so far in terms of fund raising. Our previous best was £7,000 and this year we made £8,723. We are most grateful to everyone who patronised the evening so generously and from the comments we have heard they all seem to have enjoyed themselves.

Our picture shows our Patron, HRH The Duchess of Gloucester receiving a bouquet from Helen Scott with Mr and Mrs Scott looking on.

MONEY is still coming in to the Esther Rantzen appeal and the present figure to ASBAH is £39,529.12 and to the Scottish Association £2,829.85. We really are fortunate to attract so much goodwill.

HOW'S THIS for courage? A village school in Buckinghamshire organised a sponsored walk in aid of ASBAH and raised the grand total of £529.05. What was particularly splendid was that Kevin who attends the school is spina bifida and walks with arm crutches.

It was a horrible day, very damp and cold, but most of the walkers completed 25 laps around the school field and Kevin managed to complete 16 laps raising £74 of the total. The school secretary concludes her letter with this sentence, which I think is very apt indeed, 'I think you will agree that they really did, all of them, put their best foot forward'.

ANOTHER donation of a different kind amused us. A gentleman whose hobby is backing horses decided to give up his pleasures during Lent and saved £10. He had been going to put it to the BFFHITB (Bookmakers Fund for Holidays in the Bahamas) but on seeing an advertisement about ASBAH in the Daily Telegraph he decided to send it to help our young people instead!

KATE WHITE

If you're 57 or under and severely disabled, claim Mobility Allowance now.

If you are aged 57 or under (i.e. if you were born after 13 January 1921) you should claim Mobility Allowance now.

Claims can also be made for children aged 5 or over.

This is a benefit to help severely disabled people who are unable (or almost unable) to walk.

It is up to you how you use the Mobility Allowance to help you get about. The allowance is worth £10-a-week.

Fill in the coupon so that we can send you leaflet NI.211 which includes a claim form and tells you more about the scheme. Or you can ask at your local Social Security office.

Mobility allowance

Claim now for anyone aged 5-57.

To: Mobility Allowance Unit, DHSS, Norcross, Blackpool FY5 3TA.
Please send me a copy of leaflet NI.211 about Mobility Allowance.

Name (Mr/Mrs/Miss) ____________________

Address ____________________

____

____

Postcode ____________ Age ________

Remember only claims for those aged 5-57 can be accepted now. Others under pension age will qualify later. An announcement about people aged up to 58 will be made in September.

MOBG/L.1

Issued by the Department of Health and Social Security.

CLASSIFIED 'ADS'

Adverts for next LINK must be in by August 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

GOLDEN SANDS, VORYD, RHYL, N. Wales: 8-berth caravan. Mains water, electricity, gas, shower, television. Every facility on site, right by sea. Details: Mr S. Foster, 84 Elmwood Drive, Blythe Bridge, Stoke-on-Trent.

LOOE: Well equipped 6-berth chalet at Millendreath Holiday Village. Details: Mr C. Matthews, 11 Kingsbere Ave, Wallisdown, Bournemouth, Dorset.

ISLE OF WIGHT: Brambles Chine. Holiday chalet. Open all year but fully booked May 13-Sept 16. Ring Mrs Gully, Seaview (I.O.W.) 3194.

SELSEY: Well-equipped specially designed, mobile home. 7-berth plus cot. Details (please send SAE) to: Mrs D. M. Driscoll, 26 Limes Avenue, Waddon, Croydon, CR0 4JX.

WESTGATE ON SEA: Semi-detached holiday bungalow, adapted for handicapped. Bath hoist. 10 mins walk sandy beaches. Garden. Sleeps 6/8. Details: David Randall 01-856 3436, Greenwich ASBAH.

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

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.

HURSTWOOD TRICYCLE. Hand-lever action, adjustable foot rests. Suit 2-5 yr old. Hardly used. £15. Tel: 01-658 0660.

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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.

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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.

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
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

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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.

NEW ADDRESSES

DIRECTORY OF LOCAL ASSOCIATIONS

THE FOLLOWING changes have taken place since the full Directory was published in the last LINK:—

JERSEY
Mrs T. Roberts,
Les Saules,
Parcq du Pont Marquet,
St Brelade

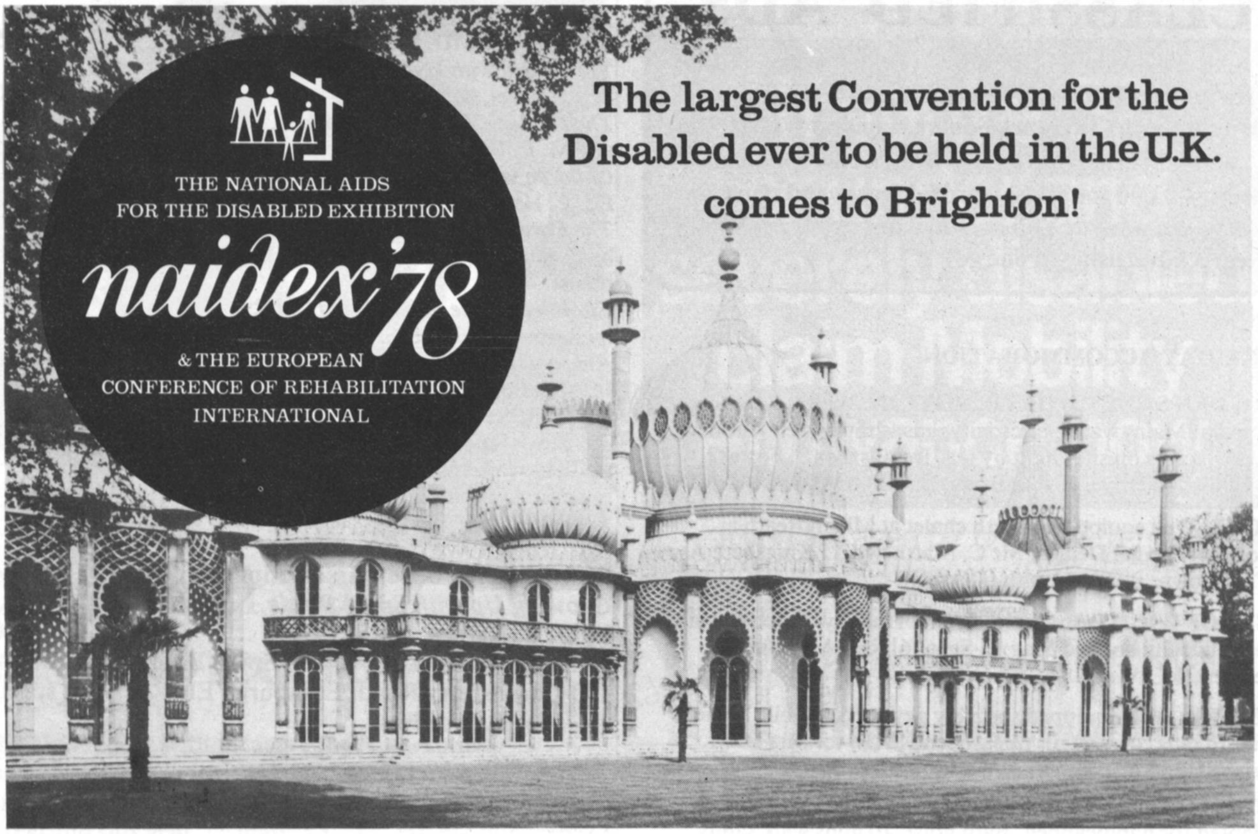
SOUTHAMPTON & DISTRICT
Miss A. E. Brayley,
94 Hillside Avenue,
Bitterne Park,
SO2 45Y

STAINES, HOUNSLOW & DISTRICT
Mrs M. McGuigan,
7 Winchester Rd,
Hanworth, Middx.
Tel: 01-894 9230

WIGAN & CHORLEY
Mrs M. Roberts,
87 Common Lane,
Culcheth,
Warrington,
Cheshire WA3 4HF
Tel: 092-576 4889

New Associations:

LLANELLI
Mrs Y. Pudner,
83 Denham Avenue,
Llanelli, Dyfed.



The largest Convention for the Disabled ever to be held in the U.K. comes to Brighton!

Already 100 major manufacturers have booked stand-space.

More than 100 manufacturers and associations will be displaying their latest aids, equipment and services for the handicapped, which includes wheelchairs, stairlifts, hoists, kitchen, bathroom and toilet equipment, electronic teaching aids and a selection of hand-controlled and welfare vehicles.

'MOTABILITY', (a scheme to provide vehicles for the handicapped) will also be represented at the exhibition, confirming the increasing importance of mobility for the severely disabled.

Running concurrently with the Exhibition will be the 2nd European Conference of 'Rehabilitation International', whose theme for 1978 is 'Disability in the Family'. Subjects to be covered in the Conference will be: Congenital, Neurological, Traumatic and Unstable Disabilities, Blindness, Deafness and Mental Handicap.

Seminars and round table discussions will also be included; covering Education, Housing, Employment and Transportation for the Disabled.

A 'Book of Abstracts' containing comprehensive details of the Conference Programme, together with accommodation, travel details and other relevant information is now available from the Organiser.

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