Link

Association for Spina Bifida and Hydrocephalus/ASBAH 20p

May/June 85

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THIS EXHORTATION by David Griffiths, one of whose many caps is that of Secretary to the West Midlands Disabled Motorists Club, was published in the club's recent Newsletter.

*We'd like **your** views on it. Moyna Gilbertson, ASBAH's Chief Executive Officer, has given ASBAH's point-of-view on page 4.*

Please write to me — Sue Gearing, LINK Editor — by June 10 if you'd like your views considered for the next issue.

WHEN YOU'VE been involved with disabled people and had contact with those who are also similarly involved for a period of time, as I have, you gradually learn to accept many things, persistently clamour for improvements in others, and, more often than not, slowly become aware of THEM.

THEY were the ones who decided public loos for disabled needed pans so high that most of us needed to be mountaineers to get on the things. WE were the sufferers, the invonvenienced, the fighters against pinnacles of peeing power, and (in most cases anyway) the subsequent victors. But not before THEY had littered the countryside with high altitude thrones.

It was THEY who decreed all DHSS wheelchairs should be blue; WE who demanded change and harmonising tones, but THEY who made instead, a decree for new unbiquitous grey ones.

Over the years, THEY have fought for what they thought we wanted, made rules we never needed, got rid of trikes many of us wanted and needed, decided we should all go to special schools, ensured the greatest possible difficulties were placed between us and the things we desired, and made unyielding rules to prevent access to benefits and allowances supposedly made available because WE fought for them.

THEY speak for us on matters departmental, Governmental, legal and so on. Yet here we are, doing precious little about it. And suffering as a result, of course.

Has it ever occurred to you just how complacent disabled people really are? That includes me, and YOU. By being complacent, things can, quietly, get worse when we are perhaps under the impression that they are only getting better. Take Blists Hill Museum at Ironbridge, for instance. We were delighted a few years ago at the helpful nature of those involved; we could take our cars and invalid cars in, see all that there was to see (admittedly less than is in the Museum today), and more than once have we enjoyed a pleasant peep into the past.

Past is the word. Today, we can't do that. Blists Hill is just about as inaccessible as the past it attempts to recreate. Gone are the days of driving in. Gone too is the convenient access point. Instead we are faced with a long uphill trek, along authentic rutted gooey tracks, past a loo supposedly for the disabled, and used, on the day I visited, as a store for cleaning materials.

All the latest acquisitions in the quest for authenticity have genuine authentic thumping great steps. No ramps to be seen anywhere, and without a mode of transport within the museum, there's no chance of negotiating the great rough hill in the middle. We are denied Telford's

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little turnpike house and the other memories down the hillside.

'Tis a sad reflection on the other sections of the Museum complex, where much has been done to accommodate the disabled, and successfully too. Making enquiries revealed it is all in a quest for authenticity; since we can't apparently have access for our vehicles, could we please have some boxes on wheels, repleat with beggar bowls and wooden sticks to propel them? Thank you, Mr. Curator.

To return to the original line of thought (I digressed, alas). It is a sad fact that the disabled themselves are responsible for precious little decision-making on their own behalf. For instance, the much vaunted BANSTEAD PLACE sports nary a limping individual where it matters; RADAR isn't much better, yet it is viewed by THEM as the mouthpiece for the Disabled. Try finding a Spina Bifida sufferer employed within the realms of ASBAH, or a principal voice in Muscular Dystrophy Groups who actually knows the terms of the disability by personal experience of it.

The Spinal Injuries Association and Mobility Information Service are probably two of the very few organisations where the disabled themselves are in control, where WE make the decisions for US, without THEM.

It should'nt be like this, and it need not be, but unless WE pull our socks up, and fight for our rights, it could always be so. Are we really so inferior to THEM that we cannot stand up united for what we need?

It is worth noting the the greatest achievements on behalf of Disabled People this decade came in America, with rights for Disabled People. Success came because Disabled People stood up and fought for themselves. Isn't this what we should all be doing? If the Disabled of a country led by an aged actor can do it, surely we can too.

DAVID GRIFFITHS

IT CAME as a surprise to read that David Griffiths believes that there are no "spina bifida sufferers employed within the realms of ASBAH," particularly since he has visited the offices and met many of the staff when he attended our Spring Conference in 1982.

His assertion is, of course, incorrect. ASBAH currently employs, on a full time basis, eight disabled people, five with spina bifida and/or hydrocephalus and three disabled in other ways. Additionally, three of the people on our register of counsellors have spina bifida and hydrocephalus. It is ASBAH's policy, also to welcome young disabled people into the office for work experience.

In addition to the numbers of disabled people actually employed by the Association, ASBAH does, of course have disabled members on every committee and working party.

MOYNA P. GILBERTSON
Executive Director

FRONT COVER

ASBAH's Patron, HRH The Duchess of Gloucester is presented with a bouquet by Maureen Wingrove a member of ASBAH's telesales department. In the background is Mrs Yvonne Cox, Chairman of Five Oaks Management Committee and an Executive Committee Member.

The occasion was a reception at London's Forum Hotel in April at which The Duchess had the opportunity of meeting young people with spina bifida and hydrocephalus who are members of LIFT. Some of ASBAH's most generous supporters were also there and presented cheques.

Altogether about 100 people attended what proved to be an informal and very friendly occasion. It will be remembered in particular by the LIFT members with whom the Duchess was able to chat for quite some time. The reception was a fitting event for this International Year of Youth.

Married woman wins care allowance

THE DHSS could have to pay out over £80 million to 'Carers,' following a test case judgement in favour of Mrs Jacqueline Drake. She appealed against the social security regulation which said that because she was a married woman, she could not receive £21.50 a week Invalid Care Allowance for looking after her disabled mother.

Supported by solicitors from the Child Poverty Action Group and Disability Alliance, Mrs Drake argued that by refusing the allowance to married women, the Government was contravening an EEC directive that there should be no sex discrimination in the social security system.

The DHSS is to appeal to the Social Security Commissioners and the case could go to the European Courts.

Judith Oliver of the Association of Carers says that following Judge Byrd's decision in favour of Mrs Drake the regulations are now technically in force and married or co-habiting women looking after disabled relatives should apply now for Invalid Care Allowance.

Check on blood test availability

A SIMPLE way of avoiding the development of serious and some times fatal shunt infections is a regular blood test, particularly in the first six months following surgery.

ASBAH is concerned to hear that some people are having difficulty in finding someone to carry out the blood test. They should be available by arrangement through your GP or Hospital Consultant.

ASBAH would like to hear from anyone experiencing this kind of difficulty. Please contact Miss Moyna Gilbertson, Executive Director at National Office.

LETTERS

Hydrocephalus support group takes shape

WHEN I first approached ASBAH concerning a Self Help Group for Hydrocephalus my initial expectations fell considerably short of the immense impact and interest which has developed so quickly. Already it has sparked a national awareness of the need for such a group and clearly indicates these early efforts will be well rewarded to the benefit of children and parents who wish to become involved.

The most encouraging response to my article in the Jan./Feb. issue of Link must, in no small measure, be attributed to ASBAH. They immediately recognized my assessment of the situation which, to their credit, necessitated a critical analysis and adaptation of their existing procedures.

With their encouragement my earlier article was published. It has resulted in approval by ASBAH to promote the formation of a Hydrocephalus Support Group. Incidentally, fund raising must feature as an important function of the Group but, for the moment, let us concentrate on getting off the ground.

My thanks to all who wrote to me — the response was overwhelming both in number and enthusiasm. I am replying to each one individually although the volume has entailed some delay — hopefully, replies will be completed by the time this follow-up article goes to press. Do not let this prevent late-comers from writing, indeed, it will help to establish contact for the future.

My next step is to visit areas throughout the country to meet the very kind (and very concerned) people who have made contact and to discuss their local requirements with a view to establishing regional groups. The generous offers of help will then be gratefully accepted. This next step has been mentioned in my individual replies and I shall communicate with you again when my visit to your area is imminent. Similar communication will be made to others who have not so far made contact, so please write to me if you are interested.

Apart from writing for the purpose of making contact, letters of general interest to our cause would be welcome, e.g. specific advice gleaned from personal experiences, case histories, successful or otherwise, and it may well be that a resumé of such letters could be incorporated in future issues of Link. Whilst on this subject, my thanks to the Editor of Link for providing space in the magazine for hydrocephalus without detracting from the much needed information to those who are also involved with spina bifida.

Finally, a reminder — letters should be addressed to: Mrs. Barbara Hay, c/o ASBAH, 22 Upper Woburn Place, London, WC1H 0EP. This applies to the first letter you write — thereafter, I shall give you my home address for direct contact.

Neil and Mark give car plan push in right direction

NEIL LEVACK, 18 of Cowes on the Isle-of-Wight needed a car of his own in order to be independent, so he did something about it, with the help of his family and friends.

Neil and his brother-in-law, Mark Hayward, had the idea of organising their own Wheel-and-Push to raise money for the Isle of Wight local assocation which had agreed to cover the cost of adapting a new car for Neil.

The 30 mile wheel-and-push by Neil and Mark round the Island — including the difficult and hilly Island Marathon course — raised over £1,000. Neil and Mark were not alone. They were accompanied by parents and friends using the association's motor caravan as a base, by members of the 69th East Cowes Nany Goat Lancers, and their mascot, Bandit the billy goat. The band rode on a lorry and played Neil and Mark all the way round.

Neil is now the proud owner of a brand new Metro Automatic (see photograph) bought through British Leyland's special scheme for handicapped people. It was bought partly with Neil's own savings and with help from the association, and from customers of the Royal Standard in Cowes. It was specially adapted, and fitted with an autochair which lifts Neil's chair onto the car roof, leaving the inside free for driver and passengers.

Everyone who had helped with fund raising was invited to Neil's 18th birthday fancy dress — everyone except Bandit the billy goat.

Neil and his new car

Mark gains top scouting award

CONGRATULATIONS to Mark Golay of Frome in Somerset who recently gained his Chief Scout Award. Mark who has been a member of Bristol and District association for many years has a similar spinal deformity to spina bifida.

Mark has also recently won six gold medals at Stoke Mandeville for swimming, and he has four British National records and trophies to his credit.

- **LINK is always pleased to hear of the achievements of young people with spina bifida and hydrocephalus. But equally it is also important that we get the chance to air some of the problems that you have encountered. Please do write to the Editor: Mrs Susan Gearing, c/o of National Office.**

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The big conference draws near

**International Federation for Hydrocephalus and Spina Bifida.
1985 Conference and General Meeting.
University of Manchester Instititute of Science and Technology
25-28 September, 1985.**

THIS International Conference, held for the first time this year in Britain, is only four months away.

It should prove a stimulating and enjoyable few days and delegates are expected from all over the world.

There is still time to book. If you do not have an application form please get in touch with ASBAH National Office.

In the details of the conference which appeared in the last LINK we omitted to give rates for people attending on just one or two days. This will be £20 per day which includes entrance to the conference and exhibitions/demonstrations, morning coffee, lunch and afternoon tea.

If you are not able to be with us for the whole conference, we hope to see you for one or two days. Attending on a daily basis does, of course, mean that you will miss out on the exciting social/entertainment programme. This has not been finalised yet, but details will soon be available.

Snowdon Award helps Dawn

LINK readers will be pleased to hear that Dawn Coleman, who is training to be a Riding Therapist at the Fortune Centre in the New Forest (LINK Nov/Dec 1984) was recently presented with a Snowdon Award. This is a financial award that will enable her to continue with her training.

Dawn needed help if she was to continue at Fortune, where she is doing so well, and ASBAH put her name forward as being someone who would benefit from the Award.

Sue's story

SUE Gorman (right) of Leicester is pictured working under the Youth Training Scheme at a Red Cross toy library. Here sue writes about the hopes and disappointments of her education and career so far . . . fortunately, we leave her on a happy note!

"I applied for a place on the Graphics and Design Course at Loughborough College but was turned down as the teacher-in-charge — who had never met me — said that I wouldn't be able to cope with the work!

"I then applied for a place on the Fashion and Design Course at the same College, but was turned down again as I failed an 'O' level which was needed. I then left school at 16.

"I had to go into hospital for an operation on my legs. I spent a month in hospital then after that a year in Alderman Newton's sixth form to take 'A' level Art and Design and retake the English Language 'O' level that I failed at school. I passed the 'O' level English but unfortunately had to drop out of college as I was having problems with my legs.

"Although I have 6 CSE and 2 'O' levels and experience as a receptionist, no-one wanted to offer me a job. After a year on the dole, and another operation, I was accepted on a YTS course at the Red Cross toy library. I spent 14 months there and then went for a job at British Telecom but didn't get it.

"But my luck changed and I was offered a job at Remploy working in the Origination Offices, and I'm now on the permanent staff list! My job really suits me as it's lithographic work and design".

Photo: Neville Chadwick

Telecom makes life easier

BRITISH Telecom's new range of public pay phones and kiosks should be good news for disabled people.

Kiosks will have entrances wide enough for wheelchairs and will be flush with the ground. Most kiosks will have no doors and be open fronted, which is just as well as doors tend to be heavy. Telephone equipments will be fitted lower than usual to be within the reach of people in wheelchairs, albeit at the highest level of their reach.

The new payphones will have press button dialling, and with the latest models, money can be more easily inserted into a single slot which takes a range of coins.

British Telecom Action is a new action group set up by BT to provide a central point of contact for 'telephone problems' of disabled people. A booklet on products and services for handicapped people is planned as one of the first tasks.

Enquiries about telephone problems should be made to BTAID, Room B5044, British Telecom Centre, 81 Newgate St, London EC1A 7AJ. Tel: 01-356 4917.

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Spina bifida, congenital hydrocephalus is on the decline in Great Britain

BY
PROFESSOR JOHN LORBER

I LAST wrote on the statistics of spina bifida births for Link in 1978. Then, encouraging figures were starting to come in about its decline. Since then, there has been a further progressive and rapid fall.

There is now a reasonable possibility that in the not-too-distant future very few babies will be born with severe spina bifida, if the present trends continue.

Active prevention together with routine antenatal diagnosis for the entire population should play an increasingly active role in achieving this.

Spina Bifida

In England and Wales there were only minor fluctuations in the number of babies born with spina bifida before 1972. In 1972 1,580 spina bifida babies were born, which represented 21 such babies per 10,000 total births. Since then, each year there has been important fall. By 1976 there were only 880 spina bifida births; in 1980, 756, and in 1983 there were only 422.

This corresponds to 6.7 per 10,000 total births or only one-third of the figure just 12 years earlier. This decline was even greater in the larger cities, presumably because of the more complete antenatal services. In every major city with births exceeding 6,000 per year, the rate per 10,000 was 5.2 or less which is below the national average.

In 1983 the lowest incidence was in the Trent Region (which includes Sheffield) with only 4 per 10,000. Even in Wales the rate dropped to 10.4 per 10,000. While this is a higher figure than in any other regional health authority, it is substantially lower than the national average only 10 years earlier.

Interestingly, enough, in the past, the rate used to be the lowest in East Anglia, and because of that it was not thought that routine antenatal serum tests were necessary and now the rate of 10.3 in East Anglia is almost the same as in Wales.

The picture is very similar in Scotland where antenatal tests are being carried out on a large scale. In 1971 there were 265 babies born with spina bifida but by 1980 this fell to only 75 and the figure has remained the same since. The incidence per 10,000 total births fell from 30 in 1971 to 11 in 1982 — a three-fold reduction, as happened in England and Wales, though the incidence remains nearly twice as high as in England and about the same as in Wales.

This major decline in spina bifida births contrasts sharply with the general, steadily increasing incidence of all other congenital malformations, such as that of the heart or chromosome defects.

This decline in Great Britain is only partly due to antenatal diagnosis followed by termination of pregnancy. Precise figures for terminations when the foetus had spina bifida are not easy to obtain but the available data indicate that less than half of the fall in spina bifida births is due to this cause. The others are due to unknown factors — possibly the improved general standard of nutrition of pregnant women. It is impossible to prove this.

Anencephaly

Antenatal diagnosis is easier and more accurate in the case of anencephaly, which is the most serious varient of the neural tube defects. It is, therefore, not surprising that anencephaly is getting even less common and by 1983 only 114 such babies were born in England and Wales. This is 1.8 per 10,000, while in 1974 it was 13.2. In the City of Sheffield there has not been a single anencephalic birth for over 3 years.

In Scotland, the fall in anencephalic births was also dramatic — from 224 in 1971 to 13 in 1982 or from 26 per 10,000 to only 2: the same as in England, in 12 years.

Congenital Hydrocephalus

The incidence of congenital hydrocephalus unassociated with spina bifida is also falling, though less rapidly. In this condition antenatal diagnosis is very rarely practised and terminations are extremely uncommon. Even so, the rate in 1974 was 4.8 per 10,000 and it dropped to 2.9 and to 3.1 between 1981 and 1983. The reason for this decline is not known and may not be permanent.

Deaths from Spina Bifida

The number of deaths from spina bifida is also rapidly declining. In 1975 in England & Wales 584 babies died under one year of age. By 1982 this figure dropped to 192. This means that approximately 60% of the babies born that year survived to one year.

This high survival rate suggests, as does my personal experience, that antenatal diagnosis tends to detect the most severe cases and a larger proportion born today are less severely affected than used to be the case. Correspondingly, the number of severely affected babies who survive with major defects is rapidly dropping.

At the same time the proportion, but not the number, of babies with simple meningocele is increasing. As babies with meningocele usually survive without handicap it is a good thing that it is not detectable by current antenatal diagnostic methods.

★ ★ ★

The information contained in this article is obtained from personal records relating to Sheffield and from its Contenital Anomalies Register. For England and Wales it is obtained from the publications of the Office of Population Censuses and Surveys. For Scotland it is from personal communication with Dr. Frances Hamilton of the Greater Glasgow Health Board and from the article "Spina Bifida and Anencephaly in Scotland" by Vera Carstairs and Susan Cole, *British Medical Journal,* vol. 289, Nov 3, 1984 1182-4.

Housing and the right kind of help must come together

SIOBHAN ROWE, BVA, Dip HA.
Accommodation & Development Officer

IDEAS about suitable living situations for people with physical disabilities have evolved significantly over the last 10-15 years, from those endorsing different forms of institutional care to the current popularity for the idea of 'living independently in the community'.

There are now many people with physical disabilities living in their own homes, receiving daily physical assistance from statutory services, such as home helps and district nurses, or from care attendent schemes run by the voluntary sector. In some cases they organise it themselves and pay for their own private care attendants.

It is becoming firmly established that the need for daily care assistance and housing does not have to be combined in the form of residental care but can, and should be separated giving disabled people the right to live in a similar way to their able-bodied counterparts.

One can assume that such opportunities will be available to more and more people in future. However, there is a danger that this movement will miss out many people who for various reasons might not fit easily into an independent living situation, even if they are supported.

There are about 15,000 people with spina bifida and/or hydrocephalus in the UK, of whom, about 85% are under 30. Spina bifida and hydrocephalus can vary in severity from mild to severe, and the interlinking of the two conditions can have a marked effect on the daily functioning of an individual. But there is no reliable way that ability can be predicted simply by looking at the severity of the handicap. Hydrocephalus is not yet particularly well understood, but it is known that it can cause problems in some cases with spatial perception, memory, co-ordination, concentration and organising ability.

Many young adults with spina bifida and hydrocephalus have gone through residential special school education. This often encourages independence but problems arise because the schools are usually small and in a fairly isolated setting. Coupled with this is the limited social experience of many disabled people, caused by a combination of factors including environmental barriers, and general discrimination.

The combined effect of medical condition and limited social experience has varied consequences in terms of the abilities of an individual and his or her aspirations.

There are many people with spina bifida and hydrocephalus who simply require accessible housing and regular, reliable physical and domestic assistance geared to their own individual needs. There is nothing special about their requirements and considering the increasing number of accessible homes being built by housing associations and progress in terms of care support opportunities, it should be easier in years to come to obtain accessible rented accommodation.

People who have less straightforward needs will find matters more difficult. In many instances they will need a more intangible type of support which may be of a pastoral rather than physical nature. It might, for example, involve being reminded about routine, helped with organisation or given other general support. It might be difficult to keep up this kind of help, which actually requires a special kind of organisation ability and experience in directing other people.

ASBAH regularly hears of young adults who will sooner or later, for various reasons, leave home. They do not need a lot of physical help but would need social support. There are rarely suitable options in their area. Neither is there very often an opportunity for them to live in shared housing situations as many young able-bodied do when they first leave home. Not only is shared housing not generally available, but integrated shared housing is very rare!

The numbers of people with spina bifida and hydrocephalus approaching their twenties, or already in their twenties, is increasing yearly. As we have seen there are some who will not find housing a problem, but there are also those whose requirements are less well matched to what is available.

Unless wider housing options are developed which allow for the necessary support to be given, and which consider the need for integrated opportunities in some types of first stage shared housing (if that is what is wanted) we might be facing a situation in which in 20 or 30 years time there will be many people with spina bifida and hydrocephalus living in residential homes while the more 'independent' are living in ordinary housing in an ordinary neighbourhood setting.

Wanted: foster homes

Barnardo's have written to LINK about two spina bifida children in their care who would benefit from loving foster homes.

Peter, 7, relies on his wheelchair, and still has a grandfather with whom he keeps in fairly regular contact. Theresa, 13, walks well with calipers. Both are described as happy, chatty children of slightly below average intelligence who need special schooling.

Barnardo's say they can consider fostering applications for these and other children from families where a parent or child has a physical handicap. They have recently placed children in such families.

Further details: Barnardo's, Homefinding Project, Tanners Lane, Barkingside, Ilford, Essex LG6 1QG.

Supakart has good track record

THE production of Supakarts is a successful enterprise by disabled people for disabled people. Speedwell Enterprises, the Slough Sheltered Workshop — part of Berkshire County Council's Social Services — employs a totally disabled work force in the manufacture of the Speedwell Supakart.

Production started in 1979 and over 250 karts have now been sold in the UK. Rotary Clubs, Lions Clubs and similar organisations have raised money for Supakarts for special schools, homes, etc. and last year Marks and Spencer donated 16 of them to handicapped younsters as part their Centenary Celebrations. Recently Blue Hawk, the Home Improvement products supplier ordered 15 supakarts to be distributed throughout the country.

Many local groups of people have had money raising events to provide a Supakart for a child they know.

The approval of the Swedish Handicap Institute in 1982 has resulted in 18 sales to Sweden and it is hoped that soon the whole of Scandinavia will be covered by agents. Supakarts have also been sold to Holland, Belgium, Eire, New Zealand and Norway and India.

The manufacturers claim that the Supakart is a well accepted mobility aid for disabled children, giving them independence, and fun, and that they have many satisfied customers.

Visitors are always welcome at the factory where Supakarts are on display — Northampton Avenue, Slough, Berks (Tel: Slough 722249).

One-Way Brake makes the going easier

THE DHSS wheelchair service has introduced a new item into the range of available accessories.

It is the 'One-Way Brake' which enables people who self-propel to travel up slopes whilst preventing the wheelchair from running backwards during rests on the way up, or in between propelling strokes.

Recent field trials have shown that it is easy to operate, effective and reliable. It can be fitted to any of the wheelchairs in the Department's Model 8 range — one brake is attached to each propelling wheel.

It should prove of real help to many wheelchair users, although those who are highly skilled or very strong can probably manage just as well without. It is of no use in the home.

For further information contact your nearest Artificial Limb and Appliance Centre.

Hawk could answer phone problem

MANY disabled people find it difficult to reach a ringing telephone in time to accept the call; often by the time they get there the caller has replaced the receiver. One solution to this problem is a cordless telephone.

RADAR has negotiated a special agreement with British Telecom enabling them to offer The Hawk Telephone to disabled people at a reduced price. The cost, inclusive of VAT, is £120 plus £2.65 for postage.

The Hawk Cordless Telephone is in two parts:

- the base unit, which requires connection to a new British Telecom telephone socket (installed by your local telephone area if required)*, and a 13 amp AC mains electricity supply;
- a portable handset which operates as a normal telephone. The handset could be carried on a wheelchair, in a large pocket or on a belt — a belt clip is provided. It is not connected to the base by wire or cable but is fitted with a small aerial.

It is possible to make and receive calls on the handset within a maximum of 100 metres from the base station under the best possible conditions.

The Hawk Cordless Telephone is produced by British Telecom and is guaranteed by them for one year from the date of connection.

If any reader would like one they should send a cheque payable to RADAR for £122.65 together with details of the address to which the telephone should be sent. (Allow 21 days for delivery).

RADAR (The Royal Association for Disability and Rehabilitation) is at: 25 Mortimer Street, London W1N 8AB. If you'd like further information ring Julia McTaggart at RADAR. Tel: 01-637 4500.

*The cost of installing a new British Telecom socket is £28 plus VAT.

Computers made accessible

COMPUTERS have proved their value as aids for the disabled both in the classroom and at home, notably as word-processors, but the real problem lies in the switchgear that will enable people with very limited motor ability to operate the computer. There are many who lack the arm that can reach, or the fingers that can work a complex keyboard.

Touch-screens are now commonplace, but reaching up to the screen can be impossible. The Cheyne Scribbler gets round this difficulty, being in effect a keyless interface that can lie flat on the table, or in the patient's lap, or even in bed, a considerable distance away from the screen.

This light-weight device, produced by Siscroft Ltd, consists of a rectangular frame with an internal aperature of 11 by 8 inches and is connected with a BBC B computer via a ribbon connector: appropriate machine-code programs are available for other computers.

The frame is scanned by infra-red beams and detects the position of the finger, fist, head-pointer or whatever is used — so it can be used for drawing simply by moving the fist or pointer inside the area of the frame. The picture on the screen is held as long as is desired, so a child can draw and paint or write on the screen several yards away.

It has other, more important, applications. In conjunction with a disc drive it can be used, like a touch-screen, to access a variety of programs that are now available for the BBC computer, and it can even be used as a keyless typewriter. It could quite easily be adapted for environmental control.

The device costs about £280, and those who are interested should contact: Mrs. Lesley Carroll, Senior Speech Therapist, The Cheyne Centre for Spastic Children, 61 Cheyne Walk, Chelsea, London SW3. Telephone 01-352 8434.

British Rail's better deal

HOLDERS of British Rail Disabled Persons Railcards will be entitled to bigger discounts from May 12 this year. These include half price travel on day returns and one third off most travel for longer stays and over longer distances. Watch out for details of these discounts.

"Access Action" in print

A NEW quarterly newsletter, *Access Action*, has been launched by the Access Committee for England. Put your name on the circulation list by contacting: Access Committee for England, 126 Albert St., London NW1 7NF. Tel: 01-482 2247.

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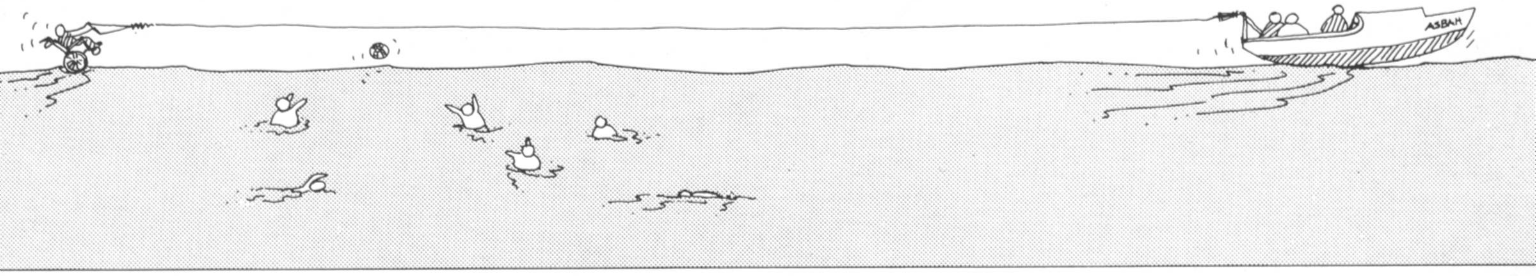


Who knows what learning to swim can lead to . . . !

A LINK Special on how to teach handicapped people the pleasures of water and swimming. Margaret Reid Campion writes about the world-renowned Halliwick method. Further copies of this feature are available from Miss Beverley Holland, Information Officer, ASBAH National Office.

Freedom of Water

The handicapped in their element

WATER as a medium for activity offers much to all of us, but for handicapped people it may well be the only place where they have the opportunity to move freely and become independent.

Most of us enjoy water and the handicapped are no exception. They want to learn to swim, and their sense of achievement when they master the art is enormous. They gain in self-confidence and self-respect and acquire a skill which is of social benefit because they can then compete with their non-handicapped contemporaries.

Widening Experience

It is well known that lack of experience of movement can result in a child's development being retarded. Water offers an excellent means of widening experience as it has both therapeutic and recreational aspects. Where therapy and recreation are based on the same method, they become complementary, and so continual rehabilitation through properly thought-out recreation can be promoted.

The method to be described is ''The Halliwick Method'', named after the school for handicapped girls in North London where it started over a quarter of a century ago. Based on a knowledge of anatomy, physiology and hydrodynamics, it has changed, and is continuing to change activity in water.

Water offers a potential for exercise in three dimensions which cannot be achieved on land. There is massive stimulation for perceptual training — visually, aurally, through temperature, and through the skin; there are buoyancy effects; respiratory effects; balance and rotational control which is critical in water; and there are psychological benefits.

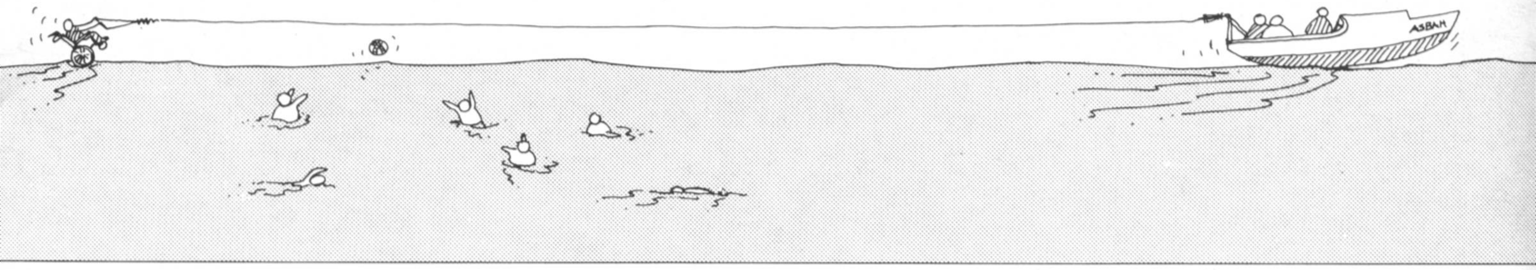
The first principle of teaching the Halliwick method is the recognition that ''no human being makes a movement except from a position of stability''. This holds good on land but becomes most noticeable in the pattern of behaviour of any person entering water for the first time. A handicapped person must learn to stabilize his body shape in the water.

A body placed in water comes under the effects of two forces — gravity and buoyancy, the former acting downwards and the latter upwards. If these two forces are not equal and opposite to each other, then movement occurs and that is one of rotation.

We need, therefore, to be able to counter any rotational effects which occur, either because of the alterered shape and density of the body or by movement of the water.

The need for consideration of shape and density in relation to spina bifida is enormous. Due to the condition, both factors will be altered, and the less dense lower limbs will have a tendency to float high in the water, making vertical rotation — or forward recovery — difficult. Children with spina bifida must learn the effect of the movement of the head on the body, especially forwards and backwards, and how good control of the head can control their body position in water. Any action that takes the head back and away, or forward and away, from the vertical will cause a quick up-swing of the legs and trunk. This loss of balance can be a disturbing experience, and it is vital, therefore, that when working with the children in the early stages, not only must the instructor be aware of the need for vertical rotational control, but he must teach this until it becomes an automatic skill.

Such movements must be kept small at first and only widened as control is gained. Vertical or forward recovery requires a quick



movement since a "sinking" action is required. The knees must be flexed towards the chin as much as possible, the head and arms stretched forwards to rotate the body from the lying position to the vertical.

Where high floating legs make the "sinking" action difficult, the arms may be carried up above the water, thus increasing the gravitational effect and, therefore, the "sinking" action. If there is a tendency for one leg to float higher than the other, then the arms would be taken up above the water and carried to the side on which the leg floats higher, thus causing rotation over that side and enabling the swimmer to get his legs down.

Coming to Terms with Water

If a child is asked whether he would like to play about in water, he would almost always reply "Yes!" Any programme of exercise should be hidden in play and can be given a positive aspect if the programme is designed to include the teaching of swimming.

Games and activities that are fun, but which at the same time are teaching the handicapped an understanding of water, how it is helping them, how they can control their bodies in water, how to breathe, and, ultimately, how to swim, should be used. Through such activities they can come to terms with water — friendly terms — because they are mentally adjusted to and physically balanced in water.

First Introduction to Water

When first introducing children to water it is advisable to break up the surface of the water as even a small pool can seem vast and frightening. Objects floating on the surface, working across a corner or to a focal point can avoid distress.

A method of entry and exit over the side of the bath, which the swimmer can ultimately achieve independently, should be taught so that should the swimmer ever find himself in a situation where there is no means of exit except over the side, he can get out of the water.

'Ears are not handles'

At all times the instructor should adopt a position which enables the swimmer to see and communicate without his balance being disturbed unduly. Gripping, holding one's breath, shutting the eyes, all increase tension so they should be discouraged, as should negative phrases much as sinking and drowning. Positive terms associated with land and safety should be used, such as "*bend your knees and sit in your chair*", "*put your head back on the pillow and lie in bed*", when you wish the swimmer to get from standing to lying supine in the water.

The swimmer must be taught how to use his head to control his body position at all times. Therefore, the instructor must not hold his head because this will destroy his chance of controlling his own body in the water. "Ears are not handles."

The simple skills of standing, walking, "jumping" — both forwards and backwards — and turning in the water must be acquired as a basis for independence and to prepare the handicapped for swimming.

Floatation Equipment

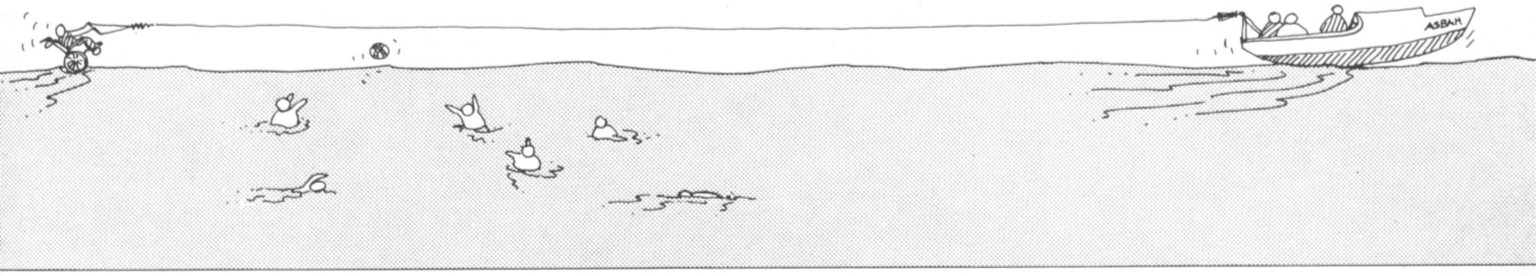
The use of floatation equipment is highly undesirable and in some cases dangeorous. Each handicapped person has a balance problem peculiar to himself, the effect of which can be changed completely or even reversed. Use of floatation equipment destroys the greatest advantage of working in the water, that of developing a finer degree of balance control.

As one headmistress put it, "Children suffering from cerebral palsy or spina bifida are blissfully content when they discard a cumbersome appliance; they blossom and find freedom of movement. Why then do we put further appliances on them in the water?"

The way in which a swimmer is held in the water can affect the development of his balance. He should always be given the minimum amount of support to allow maximum control of his own body balance. Whatever his body position in the water, he should be held at, or in line with, the centre of his body balance which is between thoracic vertebra 11 and sacral vertebra 2.

Water levels need to vary so that one can work in and out of shallower water to deeper water and back again, increasing the degree of control required. A gently sloping floor to the pool is most suitable.

Very shallow water can, in fact, be dangerous for the greater part of the body will be out of the water and gravity will be acting upon it. Any movement of the head which may cause imbalance will produce a quick fall. In deeper water the effect of such head movement would be slowed by turbulence impeding the movement; consequently, there would be more time to react and control and correct the fall.



Learning to swim the Halliwick way.

Children Blossom

Many games and activities can be devised to assist in producing a mentally adjusted, physically balanced and safe swimmer; there is no end to the skills a swimmer can acquire.

"All observers seem to agree that the benefits gained by going into the water and learning to swim ultimately are psychological as well as physical." So said an Inspector of Special Schools and Educational Psychologist.

Michael, who suffered from severe spina bifida, became so adjusted to water that he was swimming safely at the age of 6. The real triumph of this was that for the first time in his life he had achieved something before his older, normal brother of 9.

In many ways the things even the most handicapped learn in the pool are carried over into their whole life. Many who perhaps have a tendency to disregard a malfunctioning limb and so on discover the body as a whole unit, and so the pool plays a part in their total rehabilitation and overall development.

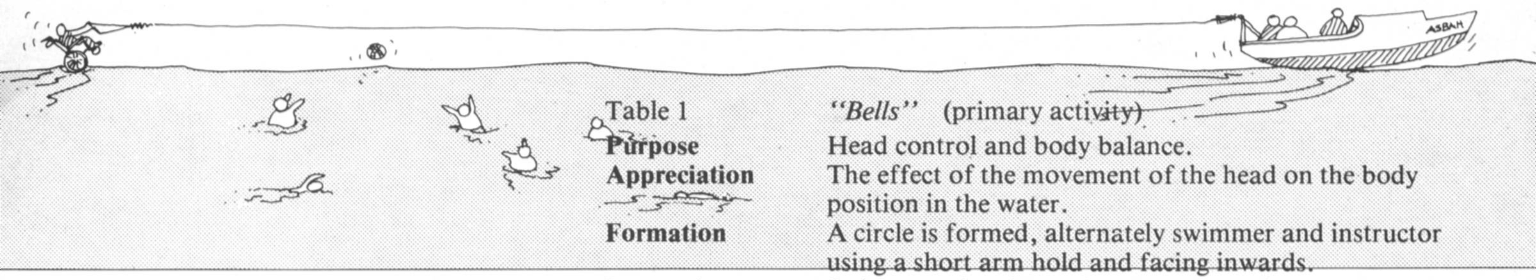
Programmes of activity should include changes of pace, position and atmosphere, as well as the fullest range of sensation.

"Ball" and "Stick"

The most stable position of a body in water is that of a "ball", so all activities begin in this position and, as control develops, so the body can be unrolled into a "stick" — the least stable position, whether in the vertical or the horizontal plane.

Games

Examples of games that keep the body in a "ball" position are: *Bells* (Table 1) and *Bicycles* (Table 2).



Kangaroo Jumps involve the swimmer in a change of posture from "stick" when standing to a "ball" as he jumps and bends his knees towards his chin, and then to a "stick" again as he comes down in the water and blows. Support in given by the istructor who faces the swimmer with his palms upwards and the swimmer's hands are placed palms down so that he has a platform from which to work. The bands should be kept under the surface of the water.

Other games which, teach forward or vertical rotational control are "Eggs for Breakfast" (Table 3) and "Rag Dolls" (Table 4). Both of these games use the "ball" and "stick" postures.

In each example only the primary part of the Activity has been quoted. Each game, however, can be made more complicated either by less assistance being given, by increasing the number of things included, and finally by making it sufficiently difficult to ensure that the skill which has been taught is carried out automatically without assistance.

Acknowledgements: My acknowledgement is due to James McMillan, MBE Hon. General Secretary of the Association of Swimming Therapy, who devised and developed the Halliwick method and to whom I owe much for his help and guidance. Also to Dr Mary Wilson, Educational Psychologist.

MRS MARGARET REID CAMPION is Lecturer in Physiotherapy, Western Australia Institute of Technology

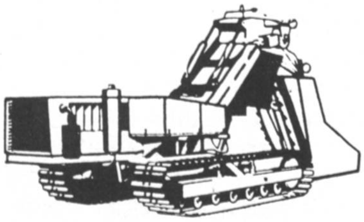
See page 27 for a Review of Mrs Reid Campion's book on hydrotherapy

Table 1	*"Bells"* (primary activity)
Purpose	Head control and body balance.
Appreciation	The effect of the movement of the head on the body position in the water.
Formation	A circle is formed, alternately swimmer and instructor using a short arm hold and facing inwards.
Instruction	Swimmers, bend your knees up towards your chests and slightly move your heads forwards and backwards.
Note	Assistance is given to the swimmers by the instructors moving their arms forwards and backwards slightly. It is important that head control, both forwards and backwards, is such that the "ball" position of the body does not swing too far. Instructors must watch the movement of the swimmers and ensure that movements remain small and that each swimmer "blows" when his face is near the water.

Table 2	*"Bicycles"* (primary activity)
Purpose	Head control and body balance.
Appreciation	Effect of the movement of the head on the body position in the water.
Formation	Swimmers are in front of their instructors, facing away and each swimmer holding his instructor's hands which are around and out in front of the swimmer.
Instruction	Swimmers, bend your knees up towards your chests and make your legs go round as on a bicycle.
Note	The instructor walks about, the swimmer "bicycles", but he must remain in the upright position. Any swing must be corrected by the swimmer's head.

Table 3	*"Eggs for Breakfast"* (primary activity)
Purpose	Forward recovery.
Appreciation	Extremes of posture and need to change shape from "stick" to "ball", to stand and lie in the water, and the need for forward movement of head and arms for forward recovery.
Formation	Swimmers stand in front of instructors, facing into centre of a circle.
Instruction	Sit in your chair, hands forward on the table, head back slowly until you are lying in bed.
Note	When the alarm goes "Eggs for Breakfast", each swimmer bends his knees, brings his head and hands forwards to reach an egg, "blows" and stands. Instructors assist the forward recovery, watching that the swimmer gets into the "ball" position, pushes forward with his head and hands, "blows", and stands and gets an egg.

Table 4	*"Rag Dolls"* (primary activity)
Purpose	Head control and forward recovery.
Appreciation	Effect of head movement on the body.
Formation	Instructors hold swimmers at waist level to one side of instructors, and will walk forwards a short distance and then backwards.
Instruction	Bend your knees, sit in your chair — head back slowly. (Instructors walk backwards a few paces.) Now bend your knees forwards and blow. (Instructors walk forwards a few paces.)
Note	Continue moving forwards and backwards in this manner, ensuring that each swimmer controls the swing of his body with his head and "blows" when his face goes near the water.



"I CAN'T GET ENOUGH OF THESE BAT BOXES FOR 'EM — THEY'RE FORMING A QUEUE!"

LINK featured Court Enterprises shortly after it opened (Issue 83, Nov/Dec 1982). This Spring the Editor paid a return visit to see how the workshop was progressing.

Court Enterprises shows it means business

IN THE Spring of 1982, Midlands Association took the bold step of becoming the first local association to start a workshop for its young adults with spina bifida and hydrocephalus. In April of that year, Court Enterprises opened with four employees — Steve Mason, Paul Jinks, Rosemary Easthope and Geraldine Coakley.

Three years later, Steve and Paul, are still happily working there — Rosemary has married and left the area, and Geraldine is unable to work — and they have been joined by eleven other young adults who, each day, spend their time on a variety of orders and work projects

They are paid a small daily rate, which has to be kept below a certain level in order that they do not start losing some of their State Benefits.

It looks as though things are working out so much so, that Midlands are looking to start another workshop in another part of Birmingham.

It hasn't all been plain sailing. Mrs Dorothy Artingstall, Chairman of Midlands Association said: "It is only in the last few months that the workshop has taken off".

The enthusiastic Manager, Bob Farmer, who joined in November suggested one reason: "We are putting ourselves out and going out to get business".

Members of the Committee have been very supportive and have helped to spread the work, Peter Coverdale, a retired executive from REACH, has proved invaluable in using his contacts to attract more work.

Business is mainly engraving. Orders come from individuals, small firms, hospitals etc. A typical request would be for name plates for office doors, or house name signs.

"We've recently started to develop the use of emblems and logos. We can engrave these on a tag, alongside the name and it seems to be a popular idea" said Bob Farmer.

Recently Court Enterprises was given a hot foil printer as a result of a Christmas appeal by Central Television. This facilitates printing on material such as leather, plastic and wood and will make it possible to produce gift items such as printed leather key rings, and wallets.

"Engraving is an ideal occupation which we can do very professionally" said Bob.

Court Enterprises used to make a good number of SHASBAH Trolleys for the DHSS, but the popularity of the trolley has waned and orders now are very few and far between.

Packing and assembly jobs are also undertaken, and Bob hopes to step up this side of the business. Photocopying and printing have also been found to be very suitable jobs for the workshop, and can be done very well and competitively.

The printing orders are usually for letterheads, invitation cards etc. Printing may be a side that could be developed, although this would involve new and more complicated machinery.

In slack times, in between orders, the employees get on with making articles such as chess sets and bird boxes. Recently they started on the production of bat boxes!

As the range of work has increased, the workshop has decided to bring out a suitable sales brochure.

Bob Farmer's arrival at Court Enterprises has put new life into the place. He was a mechanical engineer, and was involved with helping mentally handicapped children on a voluntary basis, before joining the workshop as manager.

"We do want to take on more young people", he said "and there are several of them waiting to come, but I need to have enough work to keep them busy. I think we could accommodate about 20 employees here altogether."

He has already come up against the problems of wishing to expand by way of using more machinery. Bigger and better machinery is all very well but it could mean taking out the essential labour element. Court Enterprises isn't aiming to be commercially very successful, but rather to provide a stimulating and pleasant work environment.

The 14 employees form a happy team. If any of them show real aptitude which is the case with one girl at the moment, Bob Farmer and Dorothy Artingstall will endeavour to channel them into a suitable training course which could lead to outside employment.

Court Enterprises has proved so successful in meeting a need, that the committee is now planning the next workshop and has set up a Development Fund.

"We planned five years ahead for Court Enterprises and are doing the same for the next one" said Dorothy Artingstall.

Midlands is a big association with over 400 members, and there are 100 young people under 14. With more being born each year, the need is clearly there.

The hope is that Midlands Association will get together with a local housing association to build accommodation, in conjunction with a workshop project either on the same site or nearby.

"There seems to be a great deal of interest in housing amongst our young people" said Mrs Artingstall. One of the committee members is undertaking a survey, to see what the needs might be in terms of housing in the next five years.

Steve Mason working on an engraving machine.

Court Enterprises is situated in a sturdy red brick Victorian former stable block which has been attractively renovated. The local authority has been good to the workshop asking a peppercorn rent each year, and allowing them to pay no rates. Through the Inner City Partnership — a joint enterprise between central government and West Midlands County Council — the workshop has received a £20,000 grant for the past year, and hopes this will continue for at least a further four years.

One of the recurring daily problems is transport. It takes two hours morning and night to collect all the employees and bring them in. The workshop is indebted to ambulance driver, Keith Jones who is currently unemployed and who has been doing this on a voluntary basis, Lucas recently donated a new mini bus which has made the going easier.

Court Enterprises is fortunate not only with its voluntary supporters, but in its staff. Eileen Jinks, whose son Paul is one of the employees, started out as the Care Assistant but now combines this role with helping in the workshop itself and doing all kinds of jobs. Bob Goodman is the Supervisor, ensuring that the work is done well.

The ASBAH Fieldworkers in the area, Letty Belshaw, Sue Cerfontyne and Ann Dennison keep in close touch with Court Enterprises and the Association to determine the most suitable young people to be taken on when there is a vacancy.

In order to increase parental involvement and interest, an Open Day is being planned at which parents, friends and young people coming up to school-leaving age can go along and see at first hand the success that Court Enterprises has made of its first three years.

*The catalogue will be available after June 1 from Court Enterprises, 14 Court Rd, Sparkhill, Birmingham.

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A reminder of the 1983 Road Show

Mobility Road Show aims to steer drivers in right direction

MANY OF you will remember the Mobility Road Show in 1983 — and I hope not only for the rain! That first show was so popular that the Department of Transport will be holding the Roadshow again every alternate year. This year it will be on 13, 14 and 15 June at the Transport and Road Research Laboratory at Crowthorne in Berkshire.

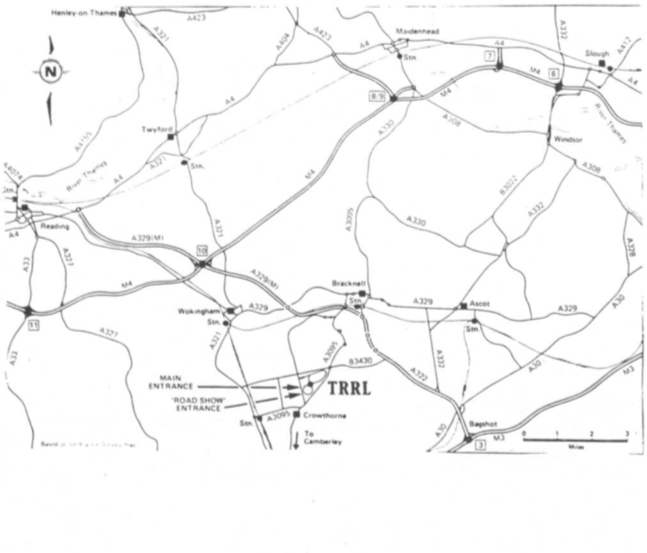
The idea of the show is to give disabled people the chance to see, try and test drive (if you have a provisional or full driving licence) a wide range of standard British and foreign cars on the test track and private road system at Crowthorne. The vehicles available for test drive by disabled visitors to the show will all be fitted with hand controls and dual controls and you will be accompanied by one of the Department's driving examiners, who will be able to offer expert advice.

The show may be of particular interest to young ASBAH members coming up to driving age and wondering what options and opportunities are open to them. Don't forget that if you are receiving Mobility Allowance you are entitled to apply for a provisional licence at 16 instead of the usual age of 17.

As well as the range of cars on display, the show will also feature special vehicles, powered wheelchair, adapted vans and caravans, hoists, hand controls and special seat belts and other mobility aids — many of which you will be able to try out as well as look at. Various organisations representing disabled people will also be on hand with specialist information. The DHSS wheelchair service and DVLC Swansea will also be there to give advice and answer queries.

So if you are recently disabled, if you are thinking of learning to drive or you are interested in changing to a new car why not make it a date in your diary to visit the Mobility Roadshow in June where you should be able to find the vehicle or equipment best suited to your needs.

Entrance to the show and the use of all facilities on offer is entirely free. The show will be open from 10.00am to 4.30pm on Thursday 13th and Friday 14th June and from 10.00am to 5.30pm on Saturday 15th June. There will be a shuttle service with wheelchair access to and from the British Rail station at Reading for those travelling by train and if you are coming to the show by road the map on this page shows motorway access to Crowthorne.



For further information about the Mobility Roadshow contact Ann Kinsella on Crowthorne (0344) 773131 Extn 2156 or the Department of Transport on 01-212 5257.

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How to be in the swim

Hydrotherapy in Paediatrics

by
Margaret Reid Campion
Lecturer in Physiotherapy, Western Austrialian Institute of Technology, Perth

published by
William Heinman Medical Books,
26 Bedford Square, London WC1

Margaret Reid Campion

. . . PROFILE

AT THE beginning of this year Margaret Reid Campion travelled from Australia for the launch of her book. 'Hydrotherapy in Paediatrics'. It is a particular pleasure for me not only to review the book but also to write a profile of her.

Margaret is the great great niece of Elizabeth Garratt Anderson, the first woman in Britain to qualify as a doctor and the hospital for women, named after her, endures despite altercations over many years. Margaret is an enormously experienced paediatric physiotherapist, having worked in numerous hospitals and schools in this country and I knew her best when we worked together at Great Ormond Street.

For many years now she has been interested in riding for the disabled and very particularly in the use of hydrotherapy especially in the Halliwick method. As far as riding is concerned, her involvement started in Devon and then London and its environs and from our point of view is significant in that she has contact with the Fortune Centre. Mrs Nelson and the Honourable Mrs Baillie met with her when they visited Australia last year. Readers will of course recall that Dawn Coleman one of our members is currently studying at the Fortune Centre and is in receipt of a Snowdon Award. There was an article about the Fortune Centre in the Nov/Dec, 1984 issue of LINK.

I really must now concentrate on Hydrotheraphy — swimming. This, I think she would agree, has always been Margaret's first love. I certainly learned a lot from her and know that there are many children and young people in particular and their families who are enormously grateful to her for the help and encouragement she has given them in gaining confidence for independent living.

The book itself is a comprehensive introduction to hydrotherapy but, for many readers of LINK, much more importantly it is a clear and detailed description of the way to introduce disabled people and encourage them to benefit from being in water. This is a book not only for professionals but for families and friends wanting to help to include disabled people, in enjoying normal family activities.

It is also a book which is enormously useful for leaders of groups. It is, as it were, a ''cookery book for swimming with disabled people''. By that I mean the suggestions in it for games to encourage various activities in water are so clearly described that one could almost have the book on the pool side and go through the activities page by page, to the enjoyment of everybody.

As far as the presentation of the book is concerned I have just one major criticism and that is in the standard of the diagrams. They are accurate and informative but the way they have been produced they may be overlooked. Do not be put off because the information they give is very helpful.

There is too, a short but sensitive section on spina bifida which I am sure both families, individuals and professionals will find helpful.

All in all I think this is a book clearly and sensitively written with many practical instructions and should be useful to everyone interested in swimming with disabled people.

● This LINK carries an article specifically on the Halliwick Method which Margaret Reid Campion wrote some time ago.

MOYNA P. GILBERTSON
MCSP, FBIM
Executive Director

Journal focuses on the churches

***ALL PEOPLE* is a quarterly journal for handicapped people, their families, friends, clergy, professionals and volunteers, who want handicapped people to play their full part in the life of the church, and the church to play a full part in the life of handicapped people.**

It is the only English language magazine concerning handicapped people in the church and was relaunched in January in the hope of attracting more readers.

The aim of the journal is to promote the place of the handicapped person in the church from every point of view. It will contain articles and news from all the churches. The first relaunched issue contained articles by Jean Vanier, the Pope's address to Faith and Light, and material on Spiritual development and the needs of the physically handicapped adolescent. In additions there were prayers by a mentally handicapped person.

It is hoped that the magazine will be able to expand in size and improve in quality if more subscribers can be attracted.

Subscriptions are £4 a year for four issues. Enquiries to *All People,* St Joseph's Centre, The Burroughs, London NW4 4TY. Tel: 01-202 3999. The Editor is Father David Wilson.

We are aiming for a million

OUR photograph of a participant in Mountain Express "getting his head down" would suggest that fundraising on behalf of ASBAH can be quite an exhausting business and certainly, as we start the new fiscal year of 1985/86, we do not anticipate a particularly restful twelve months.

The year will be something of a milestone as, for the first time, the expenditure of the Association will exceed £1,000,000. All of us in the Appeals Department regard this as a great challenge and we are therefore redoubling our efforts to ensure that this impressive target is reached.

Needless to say, there has never been a time when we have relied more on the sympathy and generosity of our regular supporters, who have made the growth of ASBAH to this significant stage possible. In order, therefore, to make sure that all our donors appreciate the importance of their contributions we are now publishing a special magazine for contributors called "Causeway", which features articles on the ambitions and achievements, plus, inevitably, the difficulties of those for whom we work and at the same time gives advance details of all ASBAH's events.

The publication will also feature items on the individual achievements of volunteers, many of whom do great things in fundraising and without whose enthusiasm we would never have reached past targets, or had the courage to aspire to future ones. If any LINK readers would like to to see a copy of "Causeway" magazine, you have only to let us know and it will be done.

The magazine is FREE, but this does not mean that it costs the Association money, as all production costs are met from advertising revenue, which also provides a substantial profit on each issue produced.

This brings us neatly to our telephone sales department which, in its new expanded form following our move to new office premises, now consists of 15 sales representatives, each of whom produces on average in excess of £1,000 per week. From this you will gather that the tele-ad department will be responsible for a significant proportion of our projected income.

ANOTHER vital area of contributions on which we are coming to rely is that of legacies. It is, as you can imagine, a sensitive task to persuade people to include our organisation in their wills, as we certainly would not wish to imply that we wished our supporters anything else than long life and the best of health. Nonetheless, testamentary contributions provide the base rock of income for most major charities and one hopes that at the time of making a will the knowledge that immense good can live on after one, brings its own satisfaction. If you would like to consider nominating ASBAH in this way, please do get in touch and we would be pleased to supply the correct form of codicil and any other advice which you might require.

DURING the coming months you will undoubtedly observe a variety of new initiatives emanating from the Appeals department, not the least of which will concern the area of trading, both by direct mail and in the high street.

ASBAH is one of the charities included in a new mail order catalogue entitled "Benefits", which offers a full range of home, garden and office goods, even new motor cards. ASBAH will receive a percentage of the value of items purchased. As with "Causeway", if you would like to receive a copy of this catalogue let us know.

Meanwhile, following the example of Barnardos, Oxfam, Help the Aged, the NSPCC and many other worthy causes, we are venturing into the area of nearly-new shops. As this is something of a departure we have been very cautious in our assessment of the market and have experimented with two temporary premises in the Hampshire area before opening the more permanent establishment in Southampton. We have been fortunate in acquiring our Southampton shop from the Council at a very low rent indeed and our Area Organiser, Mrs. Margaret Gillmore, reports that, gratifyingly, there is no shortage of either volunteer help or stock. Quite apart from trading profit, we have been interested to discover that shop premises is an excellent way of making new friends, who call in to enquire about the Association and

Continued over page

Continued from page 27

leave having agreed to run fundraising events on our behalf. Altogether a promising start and one which may lead to similar developments in other parts of the country.

IN ADDITION to the above activities we do, of course, continue to promote the varied events which have proved successful for us in the past. The Chatathon this year became more firmly established as a result of the generous sponsorship of Taylors' Port and, as always, produced a high degree of networked media coverage. This year, Mountain Express is scheduled for 17/18 August and will be run with the full involvement of HQ Wales. There is no doubt that this arduous 40 mile trek through the Brecon Beacons provides little opportunity for "going to sleep on the job" and you may be assured that the same is very much true of the work facing ASBAH's Appeals department.

JUDY KAY
Appeals Director

'Disabled need freedom to make own decisions'

***'Living Options',* the report from the Prince of Wales' Advisory Group on Disability, was launched in London in April.**

At the heart of *'Living Options'*, which ASBAH helped to produce, is a list of six 'key principles' plus 15 firm recommendations for future practice. The whole report is intended as a set of guidelines for planners in the public services. It is being sent to all health and local authorities.

The six principles stress the need for disabled people to choose their own lifestyles and to have the freedom to make decisions according to individual need.

Copies of the report can be obtained from: Mrs Nancy Robertson, Prince of Wales' Advisory Group on Disability, c/o Room 142, 222 Marylebone Road, London NW1 6JJ. 80p (including postage).

Right-to-buy made clearer

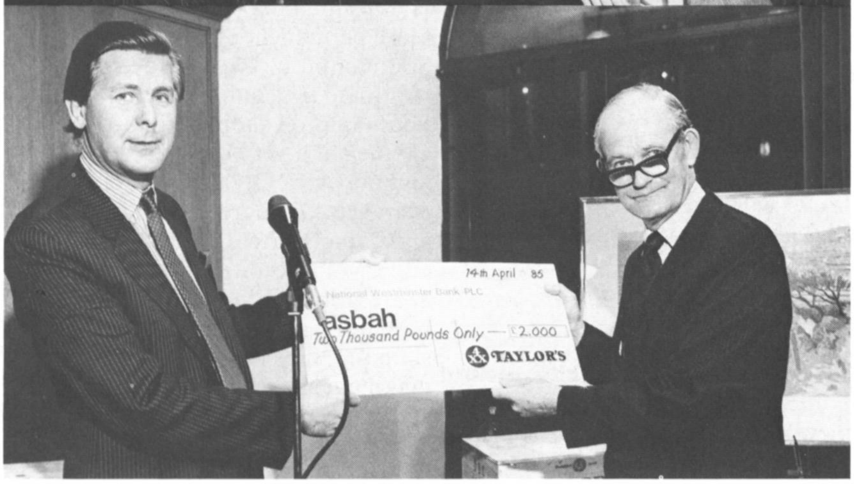
RECENT changes in the 1980 Housing and Building Control Act are designed to clarify the situation, and to ensure that disabled tenants are not denied the chance to buy if their home has only minor adaptations.

A disabled tenant will be denied the right to buy his house only if:

a. it was built or converted as a dwelling with features specially designed to make it suitable for someone with physical handicaps;

b. it has been adapted by the landlord to make it suitable for occupation by someone who is physically disabled and the adaptations include the provision of not less than 7.5 sq. metres of additional floor space, or the addition of an extra bathroom or shower room, or the installation of a vertical lift;

c. it has 'substantially different' features and is part of a sheltered scheme for the disabled.



A TOAST TO ASBAH!

The winner of this year's Chatathon, William Hall (sitting centre in the photo left) toasts ASBAH at the end of the 10 hour session of good conversation which was held at the Glazier's Hall in London.

Many of you may have seen William on 'Wogan'. He was judged to be the person with the best conversation. The 10 hours Chatathon was divided into 50 minute sessions with contestants talking to each other in pairs on a given subject.

Also in the photo, left to right;—

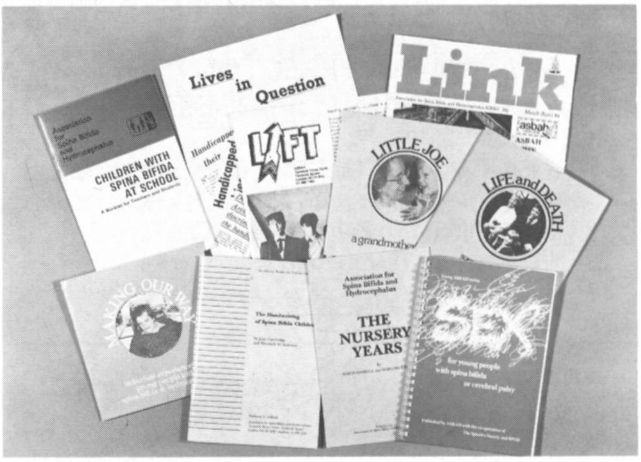
1st row: Auberon Waugh, one of the judges; William Hall; Barry Crier, another judge.

2nd row: Alistair Robertson, Managing Director of the sponsor Taylor's Port; Brian Hayes, a judge from LBC Radio; M. Hasslacher of Deinharts, the port shippers; Jonathan Wootliffe last year's winner; and Col. Seys Phillips, Master of the Glazier's Company.

Photo below left: Douglas Jack, Trusts and Businesses Fund-raiser for ASBAH receives a cheque from Alistair Robertson of Taylor's Port.

Altogether the Chatathon is expected to raise about £6,000, including sponsorship money.

ASBAH PUBLICATIONS



ASBAH is continually renewing its publications in order to keep up-to-date with information and advice on all aspects of spina bifida and hydrocephalus. Its potential readers range from parents with young spina bifida children to professionals anxious to improve the handwriting of their handicapped pupils.

In addition to the main books, there is a selection of information leaflets which cover a wide range of topics. Please ask the Information Officer, Beverley Holland, for details.

LINK is the main vehicle for keeping in regular touch and endeavours to strike a balance in its news and articles in order to inform and interest a very wide readership.

ASBAH also produces a Bulletin (alternating with LINK) which goes mainly to local Secretaries and contains important information from National ASBAH which perhaps came in too late or is not of sufficiently wide interest to go in the main magazine, LINK.

LIFT, — young ASBAH — is a vigorous and growing organisation run by young people for young people, and its magazine reflects this. It is free, so if you are 13 or over and would like to join LIFT and receive the magazine contact the LIFT office at National ASBAH.

CAUSEWAY is a new magazine from the Appeals Department for contributors (see page 27 for details).

Booklets

Your Child with Spina Bifida, Prof. J. Lorber	60p
Your Child with Hydrocephalus, Prof. J. Lorber	60p
Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH	70p
The Handwriting of Spina Bifida Children, Joan Cambridge and Elizabeth M. Anderson	£1.60p
Sex for young people with spina bifida or cerebral palsy.	£1.75p
The Nursery Years, Simon Haskell and Margaret Paull	60p
Life and Death — thoughts on bereavement.	75p
Making our Way — individual experiences of young people with spina bifida and hydrocephalus.	£1.20p
Little Joe (A Grandmother's story), Winifred Foster	40p

Research Reports

The Effects of Hydrocephalus on Vocational and Non-Vocational Training, Leonie Holgate	£2.50p
The Further Education and Vocational Training Of Young People With Spina Bifida and Hydrocephalus, Hazel Benner	£2.50

All the above prices are inclusive of postage and packing.

Leaflets

Lives in Question	30p
Information leaflets	100 for £4
Fact sheets — (on a wide variety of subjects)	up to 10 copies free

Asian language translations of a Fact Sheet about spina bifida and hydrocephalus and ASBAH's work are available free (up to 10 copies) from national office. Translations are into Bengali, Gujarati, Hindu, Punjabi and Urdu.

Welsh language sheets are also available — up to 10 copies free.

Please send at least 30p postage.

Magazines

LINK. Bi monthly magazine. Annual subscription including p & p. (see page 29 for fuller details)	£3.30p
LIFT. Magazine for members of LIFT — young ASBAH	Free
CAUSEWAY — new magazine for contributors to ASBAH's work (see page 27)	Free

Films and slides

Appeal For ASBAH — For Hire. 16mm colour film, 8 mins.	£4.00p + 60p VAT
Living With Spina Bifida Slide Sets and Notes (12 slides)	£5.25p + 75p VAT

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Adverts for the next LINK (July/Aug.) should be in by June 8. Send to the Editor Mrs Susan Gearing at home: The Gables, Long Lane, Wrington, Avon. Tel: Wrington 862279.

HOLIDAY ACCOMMODATION

SELSEY, Sussex. Purpose built 7 berth mobile home, fully equipped for wheelchair users. Cot available. Licensed site. Details: Mrs M. Holmes, 11 Grove Road, Ashtead, Surrey. Tel: Ashtead 76730.

HEYSHAM, Nr. Morecambe. Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 5 Roman Way, Whitchurch, Shropshire. Tel: Whitchurch 3691.

WINTERTON-ON-SEA, Nr. Gt. Yarmouth. Fully equipped chalet. Sleeps 6. Indoor heated pool, shop, amusements, take-away snacks, club room, play areas. Details: Mr R. Morris (0494) 32184.

CENARTH, W. Wales. Luxury chalet adapted for wheelchair. Sleeps 6, Colour TV. Heated pool, restaurant, shop, launderette. Details: Mr T. Noon, 14 The Chase, Leicester LE3 2WA. Tel: 0533 895691.

WINTERTON-ON-SEA, Nr. Gt. Yarmouth. Fully equipped chalet. Sleeps 6. Indoor heated pool, shop, amusements, snacks, club, play areas. Details: Mrs A. May, 20 Ridley Close, Blaby, Leicester. Tel: 773395.

LOOE, Cornwall. Self-catering bungalow suitable for wheelchairs. Sleeps 4/7. Well furnished and equipped. Colour TV. On holiday site. From £45 per week. Details: P. Cash, Farriers, School Road, Bransgore, Christchurch, Dorset.

WESTWARD HO!, North Devon. Holiday bungalow, sleeps six. Excellent club, swimming pool. Shop on site. Near sandy beach. S.A.E. to Mr G. Oakley, 12 Farleigh Road, Perton, Wolverhampton. Tel: 751484.

ISLE OF WIGHT. Very well equipped chalet with easy wheelchair access. Sleeps 6. Indoor heated pool, club, shop. Details: Ring or write: Mrs S. Gully, Old Princelett, Apse Heath, Sandown, Isle-of-Wight. Tel: I.O.W. 863354.

EXMOUTH, Devon. Fully equipped, self-catering 2 bedroom bungalow. Central heating. Approx 1 mile from town centre. Details: J. Harper, 70 Grove Road, Harpenden, Herts. Tel: (05827) 69213.

SELSEY, Sussex. Luxury 6-berth purpose built mobile home. Excellent club site amenities, pool, etc. Details Mrs Bugden, 27 The Grove, Sholing, Southampton. Tel: Southampton 444921.

BORTH, Nr Aberystwyth. 6-berth de luxe holiday home. Licensed site. Suitable for wheelchair users who live independently. Details: J. Carter, 1 Meadow Road, Craven Arms, Shropshire.

PRIMROSE VALLEY. Fully adapted luxury caravan, sleeps 6. Shower, toilets, ramp. Many facilities on site. Details: Mr R. Vicary, 3 Wheatley Lane, Ben Rhydding, Ilkley, Yorks. Tel: Ilkley 607076.

CLACTON-ON-SEA. Hylands Chalet Park. 6-berth chalet with outdoor pool, shop and clubhouse. Equipped with elec. cooker, fridge, shower, TV. 5 mins walk village with supermarket, shop and banks. Details: Mrs Bashford. Tel: 01 735 5489.

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Don't forget to send in your advertisement to LINK for anything for sale or exchange, or wanted.

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Leisure Wear: White cotton **Tee Shirts** with green family symbol and words 'Support Spina Bifida'. Also **Sweat Shirts** in reverse colours. All sizes. Details from Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks. (Bucks and E. Berks association.)

Ortho Kinetic Chair for sale. £100 or offers. Please apply to: The Secretary, KASBAH, 4 Scott Close, Ditton, Maidstone, Kent.

Don't forget to send in your advertisement to LINK for anything for sale, or wanted, or for exchange.

LINK

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Tel: Highcliffe 3255.

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Tel: Bristol 777942.

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