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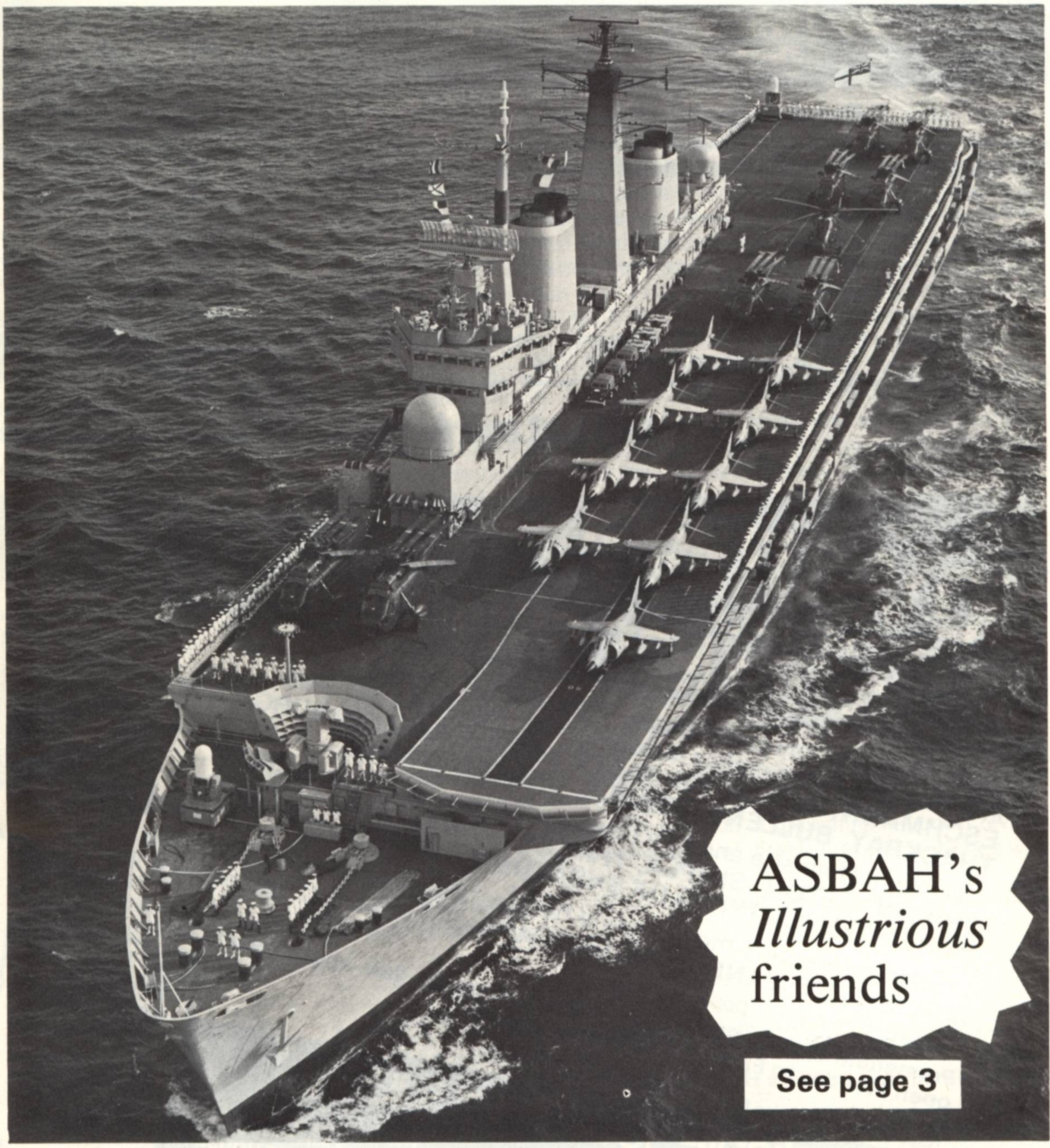
Association for Spina Bifida and Hydrocephalus/ASBAH 20p May / June 83



ASBAH's *Illustrious* friends

See page 3

★★ Bumper 28 page LINK ★★

A visit to Israel: New ASBAH publication: SPRING CONFERENCE REPORT: Coping with bowel incontinence.

LINK 86

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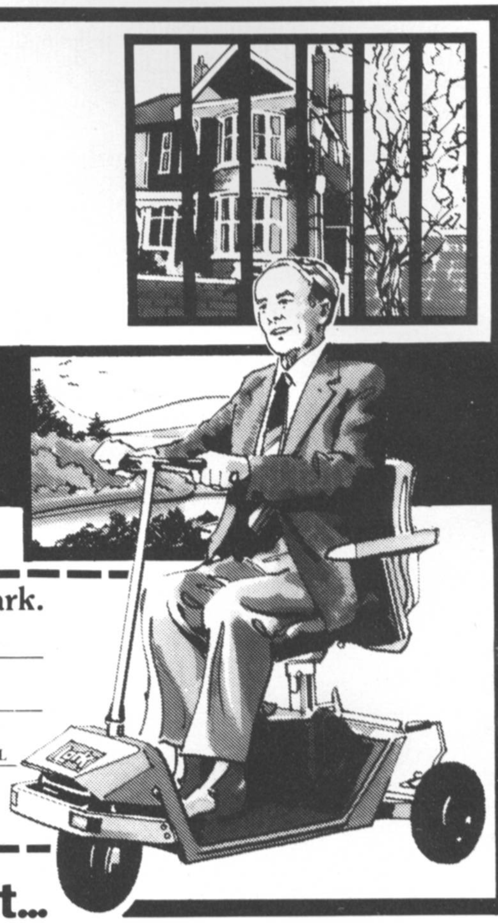

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Association for Spina Bifida and Hydrocephalus/ASBAH

Correspondence to ASBAH at the National Office:
Tavistock House North,
Tavistock Square,
London WC1H 9HJ.
Registered Charity No. 249338
Tel: 01-388 1382/5

CONTENTS

Pages

Bill fails on lack of evidence of discrimination

The Disablement (Prohibition of Unjustified Discrimination) Bill introduced by Donald Stewart, MP, was talked out when it was debated in the House in February.

Following this, ASBAH received this letter from Paul Moores of the Department of Health and Social Security:

"The Bill was, as you will know, debated in the House on 11 February. Although it failed to obtain a Second Reading, the debate provided a valuable opportunity for the House to discuss this very important issue.

As Mr Hugh Rossi (Minister for the Disabled) said during the debate, the Government does not believe that sufficient firm evidence of discrimination has been produced, either by the CORAD Report or subsequently, to justify the establishment of a regulatory machinery such as that envisaged in the Bill. It appears, too, that disabled people themselves are divided on the need for this. We would be the only European country to have such legislation, and the experience from countries elsewhere that have tried it does not convince the Government that this is an effective and practicable way to tackle the problems disabled people face. Of course, the Minister recognises that where it occurs, discrimination is very hurtful to the victim, and should be countered. He made plain in the House that he sees it as his role as Minister for the Disabled to take up individual cases put to him by disability organisations or MPs where there is serious evidence of discrimination. He hopes that this invitation will be taken seriously, and that in this way he will be able to look at the evidence more closely, and assess the extent of discrimination and the form it takes.

The Minister stressed that our overall aim should be, however, to continue to try and promote the integration of disabled people in our community, by increasing public awareness of the barriers often needlessly placed in their way through misunderstanding or ignorance about their needs and abilities. One of the key problem areas here is that of Access. This emerged clearly from the CORAD Report, and the Government is taking active steps to bring about improvements. Last month, John Stanley, Minister for Housing and Construction at the Department of the Environment, announced his intention to consult on an amendment to the Building Regulations to include access requirements for new buildings. This announcement was widely welcomed as a strengthening of the provisions already contained in the Disabled Persons Act 1981. During the debate on 11 February, Mr Rossi also announced that an English Access Committee would be set up to act as a national focus on access problems. CORAD recommended such a committee and the Minister will be consulting interested bodies on the details of its nature and activities.

While the Government has a great deal of sympathy with the supporters of legislation, and takes their arguments very seriously, it feels that the approach outlined of keeping the question of discrimination under review while actively furthering the integration of disabled people, is the best way forward."

- *ASBAH would still like to hear from anyone who has specific examples of discrimination.*

COVER PHOTO: A magnificent photo of Britain's newest warship — HMS ILLUSTRIOUS.

The ship's company has adopted ASBAH as one of two charities which it will be supporting.

So with the backing of such "illustrious" friends — 1,000 officers and men — it's very good news indeed for ASBAH. (See page 25 for more appeals news.)

New Parking Regulations

THE NEW Orange Badge parking regulations came into effect on March 16 and clarify who is, and — equally important — who is not, entitled to an Orange Badge. The rear car sticker — the cause of so much confusion — is to be abolished.

Clearly there has been illegal and unfair use of the OBS (Orange Badge Scheme) in the past, but how wisespread this was, is uncertain. Let us hope that the new scheme results in less abuse and preserves the Badge for those who really need it and for whom it is an extremely valuable mobility aid.

The new criteria for eligibility are tightly defined. The following groups of people are entitled to an Orange Badge: recipients of Mobility Allowances; drivers of an invalid tricycle or DHSS car, or those in receipt of a grant from the DHSS in respect of their own vehicle; registered blind; those who have a permanent and substantial disability which causes inability to walk, or very considerable difficulty in walking.

This last category is for people who could claim Mobility Allowance but do not, or are over the age limit. It also covers people whose personal mobility is slightly greater than that required to receive the Mobility Allowance, but who are incapable of shopping or visiting other places unless they can park nearby. Entitlement depends on the ability to walk and considerations such as the ability to carry parcels cannot be taken into account.

Badges can be issued to institutions which provide transport for disabled people. They should only use the Badge when carrying people who would be entitled to their own badge.

If an institution caters for a very small number of disabled people it may be better for those people to apply for their own badge which could be used on the vehicle in which they travel, regardlesss of who owns it.

A local authority may refuse to issued a Badge where the applicant has misused a Badge on three occasions which have led to a relevant conviction. If a person who is not the Badge holder uses the Badge when the person to whom it was issued is not being carried, the holder may be liable for conviction. It is, therefore, important that Orange Badge holders do not permit able-bodied friends or relatives to use the Badge illegally as they may lose their entitlement to it.

There is an appeals procedure. If a person who is normally entitled to a Badge is refused one on the grounds of misuse, or a current Badge is withdrawn on such grounds, he may appeal to the Secretary of State within 28 days.

During the course of the next three years, the old circular Orange Badge will be replaced by a square one which shows more clearly the expiry date. Local authorities have been requested to issue an adhesive container for the Badge which will enable the Badge to be removed or turned around when it is not in use. A local authority may charge £2 for a Badge, but many authorities do not charge at all.

As before the Scheme does not apply in Central London.

Pop group, Human League recently received a Golden Reel Award for its successful album 'Dare'. The award is given by Ampex to artistes and groups who make their master recordings on Ampex professional audio tape, and who achieve outstanding sales success.

As part of the award, Ampex give 1,000 to a chosen charity — in this instance to ASBAH. Miss Moyna Gilbertson of ASBAH is pictured with Adrian Wright of Human League (2nd right front row) and representatives of Ampex and the Genetic Sound Studios.

Professionals attend Study Day

ASBAH's Study Day in February, to look at the results of its two research projects into the effects of hydrocephalus on vocational and pre-vocational training was very well attended.

There were professionals from many different disciplines concerned with the education and care of young handicapped people, and the day's proceedings were chaired by Mr Norman Clegg, Principal of North Nottinghamshire College of Further Education, a college which has shown itself to be particularly aware and sensitive to the needs of students with physical and mental handicaps.

Mrs Hazel Benner spoke about her work at Derwen Training College for the Disabled, into how young hydrocephalic students coped with further education and vocational training, and Mrs Leonie Holgate discussed her research work, concentrating on the perceptual learning, and social problems experienced by young people with spina bifida and hydrocephalus.

ASBAH will be producing a booklet shortly giving information about these two important projects.

Prince Charles heads advice group

FOLLOWING his patronage of the International Year of Disabled People, HRH The Prince of Wales has now agreed to be President of a new Advisory Group on Disability.

He had been asked by many organisations and individuals to provide a focus for further action to promote the ideas of IYDP.

Chairman of the Group is Lady Marre, CBE. It will aim to provide advice and guidance for disabled people and individuals, and to provide a central point for organisations wishing to co-operate with others. It is not planning to offer financial help.

Enquiries to the Director, Mr Maurice Glassman, The Prince of Wales' Advisory Group on Disability, c/o IBM United Kingdom Ltd, 15 Lodge Road, London NW8 8NX. Tel: 01-935 6600, ext. 5214.

Waveney sets housing example

AT THE end of IYDP the National House-Building Council launched an award scheme for local authorities who had encouraged the building for sale of housing for elderly and disabled people. This Spring the award was presented by John Stanley, Minister for Housing and Construction, to Waveney District Council.

Waveney had prepared a detailed performance brief and made land available for a building firm, Ellis Homes Ltd, to build 20 bungalows for elderly people at Green Drive, Lowestoft. The whole project took only 15 months from inception to completion and flexible purchase arrangements were provided. The assessors felt that the procedures adopted by Waveney could be followed by other authorities.

A new path to gardening

A GARDENING Unit has been set up by Horticultural Therapy together with Fisons Horticulture to provide a service to help disabled people develop their interest in gardening.

A recent research study of the disabled population in Cheltenham revealed 'little or no knowledge of organisations giving advice to disabled gardeners, or of the availability of tools designed for the physically handicapped'.

The unit will be running a 'Gardening is for Everyone' exhibit at the International Garden Festival in Liverpool next year. In conjunction with this, a series of workshops will be run to provide specific practical advice to small groups of disabled people.

Other developments in the Gardening Unit will be a Garden Advisory Service and the setting up of local horticultural therapy groups. For further information contact: Tim Spurgeon, Gardening Unit, Horticultural Therapy, Goulds Ground, Vallis Way, Frome, Somerset. BA11 3DW.

Opportunity for a break

A VOLUNTARY organisation which runs small family homes for young people by the sea in East Sussex, is offering to give mentally or physically handicapped youngsters a holiday, thus enabling parents to take a break and to 'recharge their batteries'

The Fellowship of St Nicholas is based at St Leonards on Sea. If you would like more details contact the Secretary, at 25 Stockleigh Road, St Leonards, East Sussex, TN38 0JP. Tel: 0424 423683.

The PATH to drama

PATH PRODUCTIONS is a voluntary organisation, set up in IYDP, to provide an opportunity for physically handicapped, mentally disabled and able-bodied performers to create theatre together.

The group meets in the South London/Sevenoaks area and would welcome enquiries from new members. The work is basically experimental workshop-style drama, but two productions have been put on so far — the Tinder Box at the Mermaid Theatre, London in 1982, and this year, Miranda's Dream, at the Young Vic.

Enquiries to: Norma Cohen, Path Productions, 14 Stannard Road, London E8. Tel: 01-249 3512.

Sparkle is ready for sail

"SPARKLE" is a specially designed day boat for would-be sailors confined to wheelchairs. She was provided by SPARKS (Sportsmen Pledged to Aid Research into Crippling), and is completely financed by that organisation.

She is designed for 10 wheelchair users and 2 able-bodied helpers. Individuals can be joined up with a group. Physically handicapped children must be over the age of 9.

"SPARKLE" will operate at the following resorts during 1983:— 1-22 May — POOLE, Dorset; 28 May-19 June — BRIGHTON, Sussex; 25 June-17 July — CHICHESTER, Sussex; 27 July-4 Sept. — PLYMOUTH, Devon; 14 Sept.-2 Oct. — POOLE, Dorset.

The catamaran will operate every day except Monday and Tuesday.

Application forms are obtainable from the following addresses:—

Brighton & Poole: J Turnbull, Master, S V Sparkle, Cobbs Quay, Hamworthy, Poole, Dorset. Tel: Sturminster Marshall 857438.

Chichester: A H James Esq, Principal Day and Residential Care Officer, Social Services, Muir House, Broadwater Road, Worthing, West Sussex BN14 8HY. Tel: Worthing 210714.

Plymouth: R J Baker Esq, Welfare Officer for the Handicapped, Plymouth Guild of Community Service, Ernest English House, Buckwell Street, Plymouth, Devon PL1 2DB. Tel: Plymouth 665084.

The number to ring

A FREE telephone advisory service has been set up to try and help with the proper setting up and use of the ROHO Cushion. This is an aid for preventing and treating pressure sores, manufactured by Raymar.

Raymar say it is important that the cushion is used correctly and sitting pressures assessed individually.

The telephone advice could, if necessary, be followed up by a personal visit by Raymar personnel. There is also a 14-day sale-or-return trial scheme for the cushion.

The adviser on the other end of the phone is Miss Wendy Lambie: 04912 78446.

Kerry Doswell, 16, of Marden, in Kent, who despite spending the last two years fighting against pain and coping with several operations, has gained the much coveted Queen's Guide Award. Kerry, Patrol Leader of the 1st Marden Guides achieved her goal, and was presented with the Award earlier this year. Marden Guider, Sheila Wright said "It's a great achievement. She has perseverance and cheerfulness". Photo: S. Eastern Newspapers.

Teenagers get their own Scootas

THREE teenage members of the Crawley Branch of Sussex Association, Sherry Austin, Susan Manuel and Colin Burgess were recently presented with three electric Scootas. The money for the Scootas was raised from a bowling marathon and darts tournament.

This branch now has five Scootas — the other two were presented at the end of last year as a result of the efforts of Mr Fred Blackley who took part in the London Marathon.

LIFT Holiday

Lake District beckons

IF YOU are aged 18-30 and fancy a week's activity holiday in the Lake District, then read on. . . .

LIFT, (Young ASBAH) is organising a holiday for a mixed group of 36 members and able-bodied people over 18 at the Calvert Trust Adventure Centre at Little Crossthwaite, this is just north of Keswick.

It is beautifully situated on the shores of Bassenthwaite Lake and on the lower slopes of Skiddaw.

The idea is that the LIFT members who get involved should be able to continue the activities they try when they return home. These will include sailing, fishing, and canoeing.

The Trust has an indoor swimming pool where canoeing can be practised before taking to the lake. There is a nature trail and bird-watching facilities, and on the outskirts of Keswick is the Trust's stable. All activities will be supervised by the specially trained instructors and the centre itself has been designed for use by disabled 'adventurers'.

ASBAH's Disabled Living Advisers will be there to deal with 'emergencies' but all participants should be as independent as possible in all aspects of personal care.

A special seventh birthday present for Nichola Cope, from Penge in South London — a visit from Floella Benjamin from the BBC TV programme, Playschool. Floella, along with Humpty, paid a visit to Nicola and helped to open all her presents. Nicola is a pupil at Marjorie McClure School in Chislehurst, Kent.

LIFT has received a £1,700 grant for the holiday from the Royal Wedding Fund, and, therefore, the cost for each person is very low — around £40 each plus travel. This includes all the facilities above.

Write to Paul Cooper, LIFT Organiser, at ASBAH National Office for an application form and more details.

Della is group's first Queen's Scout

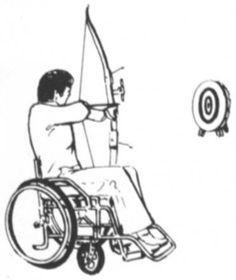
CONGRATULATIONS to Della Skidmore, a member of Bowman Venture Unit of Chiddingfold Scout Group in Surrey, who recently became the group's first Queen's Scout.

Della, 20, who has spina bifida and is in a wheelchair, was presented with the Award by the District Commissioner. He congratulated Della on her hard work, determination and endurance and also paid tribute to the other members of the group who had given her their support.

Play along with . . .

CALLING all flute and recorder players in the London Area — Mrs Ros Clayton is holding a musical 'Play Along' in aid of ASBAH on Sunday, June 26, at 3 pm and would like to hear from musicians who would like to join in. Contact her on 01-607 4814.

Regulars at the Green Dragon in Beverley, Yorkshire, and rugby players, got together and as a result raised over £1,196 for Hull and District Association. In the picture are Mrs Linda Armstrong, landlady of the Green Dragon and Mr Howard Joy, treasurer of Beverley Rugby Union Club, handing over the cheque to the Hull Association Secretary, Mrs. Gerritje Brown. The landlord's young daughter has hydrocephalus, and this spurred on customers and rugby men to organise rugby matches and a sponsored walk for the Association in Hull. Photo: Hull Daily Mail.



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Tel: (01) 648-6291 Telex: 927045 L5/6/83

Key scheme

AN UP-DATED list of local authorities taking part in the National Key Scheme for Toilets for Disabled People is now available from the Housing and Access Department of RADAR, 25 Mortimer Street, London W1N 8AB.

A key for use in the standard lock can also be supplied, price £2.

The following authorities have now also adopted the scheme: Boston, Pendle, South Holland, Tendring, Tynedale, West Derbys, Caithness, Birmingham, Lewes and Ribble Valley.

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Everest & Jennings
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LK1

Moyna Gilbertson reflects on a 'whirlwind' holiday

Exciting Israel extends a welcoming hand

EXCELLENT food, friendliness, unobtrusive help and many accessible facilities are some of the main impressions I brought back with me after a whirlwind week's working holiday in Israel. It is a land of great beauty and interest.

We were there during one of the worst winters in living memory, and saw the unusual sights of the Jordan in flood and a green desert. The contrast of leisure and conflict was evident too. It was certainly a little strange when Gabby, our Kibbutz host, suddenly appeared in guard uniform as we were having a night-cap, but it was very re-assuring to see an example of vigilance.

It was in March that I was lucky enough to join a group travelling to Israel at the invitation of the Israeli Tourist Board and El-Al to look at facilities for disabled travellers. There were 16 of us in the party, including Mr Wiser of El-Al and his wife, David and Susan Bates, our travel agents, and five people in wheelchairs.

As far as the flight from Heathrow was concerned El-Al were extremely co-operative, and the food was good.

I think it would have been a good idea if the able-bodied helpers in the group had had some instruction beforehand as to the sort of aid they may be required to give. It is difficult in an aircraft if you don't know precisely what needs to be done.

At Tel-Aviv a very sensible vehicle was used to unload wheelchairs, and everything at the airport seemed reasonably accessible.

Holidaymakers discover that Jaffa is the place to eat Jaffa oranges.
(Moyna Gilbertson is fourth from the left.)

As this was a working tour, the programme was hectic, and during the week we travelled as far North as the Lebanese border, and South to the Dead Sea. Of course we also saw the Scrolls.

We used a small bus, converted to take three clamped wheelchairs. Moyshe the driver was with us for the whole week and became very much one of the party, despite the language problems that some of us had.

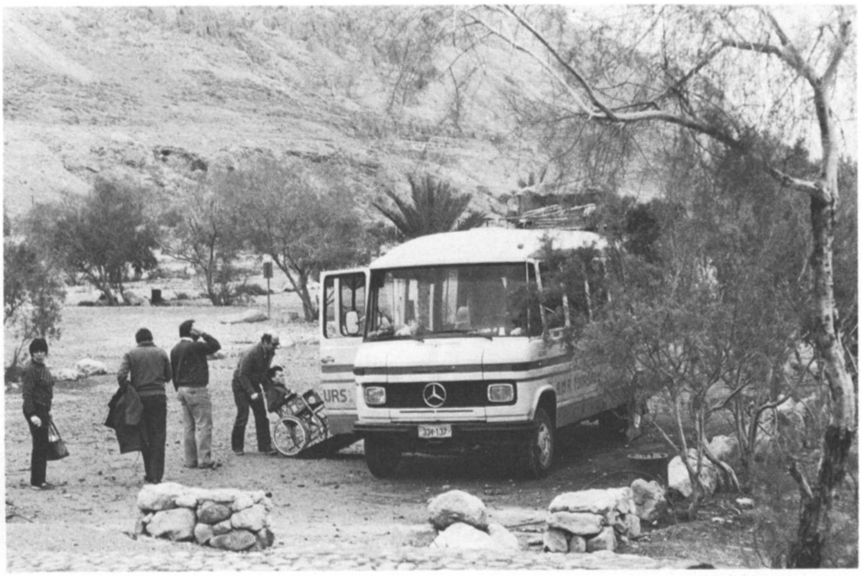
We visited Tel-Aviv and Old Jaffa — which in theory is accessible, but in practice, only so with difficulty, as the ramps are very steep and rather narrow. We saw the excavation sites at Caesarea, and although access was difficult, the attitude of the Israelis was splendid and our bus was allowed to drive in so that we had a really good view of the Amphitheatre without having to unload the wheelchairs. We enjoyed an interesting coach tour of Haifa, and at Acre some of us went up to the wall. There were ramps there as well but again they were very steep and ridged and not at all easy for wheelchairs.

The Church of the Annunciation, Nazareth. Some problems to be overcome.

The lectures we had some evenings were a very good idea, relevant to our visit — talks on lifestyle, history, and daily life in Kibbutzim, etc.

I remember the lovely church of Joseph at Nazareth, and the excellent Kibbutz nearby, where a new wing is being completed with 15 rooms especially designed for disabled travellers.

We drove into the Golan Heights, and down the Jordan Valley, and of course, visited Bethlehem. One impression of Bethlehem is how near everything is — the shepherds didn't have far to walk!



The party on the shore of the Dead Sea.

The photographs on these pages were taken by Arthur Goldthorpe, Yorkshire Association for the Disabled, who was one of the wheelchair members of the party.

Thanks to the work put in by Danny Steinberg, the travel agent organising all the details in Israel, our visit to Jerusalem went smoothly and was absolutely fascinating. He had worked out the best route, and his way it was perfectly possible to get wheelchairs through the old city. Danny who stayed with us throughout the week, proved much better than the professional guide provided in Jerusalem.

We thoroughly enjoyed the relaxed atmosphere and friendly welcome of the Kibbutzim where we stayed, although they all varied greatly. They are not all completely accessible, but there were no insuperable problems and the food was delicious. There was a common problem — bathrooms with doors too narrow, but as there was an obvious discrepancy in the size of doors in different rooms, it would be worth giving the size of your chair when booking and ask for the bathroom door to be checked.

One general tip that applies to so many holidays — make sure that all your shoes are very comfortable!

The week was an unforgettable experience, and I am not going to try and identify the highlight. But if you are thinking of holidaying in Israel, we have masses of information at National Office as well as many general holiday hints, so do remember to contact us.

I have only one regret, because our day in Jerusalem was so packed we ran late in spite of all our best efforts and so our visit to Alyn hospital where Tirza Ilan had arranged a lovely programme was very curtailed, and we did not have time to plant a tree to help make Israel green.

I shall simply have to go back!

MOYNA P GILBERTSON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Life and Death.

Published by ASBAH.
Price 75p plus postage from National Office.

MANY parents of children with spina bifida live with the fear that their child might die at any time. It is not a fear that is easy to acknowledge, or with which one can readily come to terms. Nor is death an easy subject to discuss.

However, experience has shown that the ability to face up to the possibility of death, to see it as a part of living, and to have some knowledge of how one might feel or react, can be a real help and comfort to parents and relatives.

Young people with spina bifida may also wish to talk about death, but be fearful of doing so.

This booklet, *Life and Death,* has been written to bring into the open the subject of dying. It contains articles from professionals who have experience of working with bereaved families, and personal stories from parents who have lost children with spina bifida. It also looks at the views of young people with spina bifida and hydrocephalus on the subject of dying.

It has been edited by LINK Editor Susan Gearing, and ASBAH hopes that it will prove a useful addition to its publications. Its design is the same as that of Little Joe — a grandmother's story.

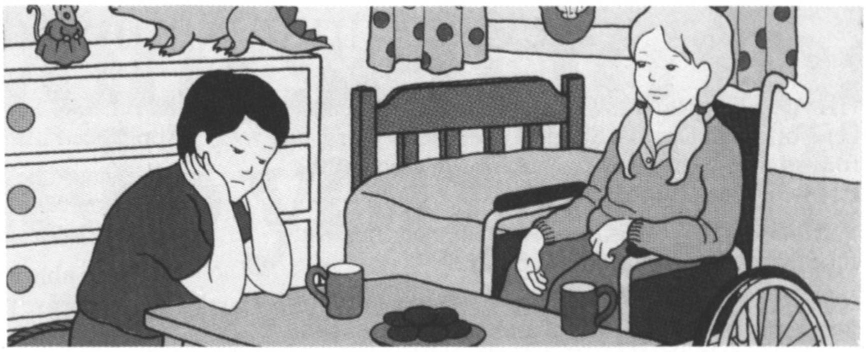
The Mobility of Disabled People in a Rural Environment.

by Jean Buchanan.
From RADAR, 25 Mortimer Street, London W1N 8AB.
Price £2 plus 50p post and packing.

THIS BOOK is the result of a major study of the mobility problems of the disabled in rural areas. Over half of those interviewed had difficulty in leaving their homes, largely because public transport was poor, or not accessible.

The main modes of transport were mini-buses, or cars provided by Social Services Departments or volunteer drivers. The private car was the most convenient form of transport, although only 23% of people drove themselves.

The closure of village stores and sub-post offices had made shopping even more difficult. The book offers some solutions. The report calls for more positive use to be made of the village hall, which was often accessible to the disabled.



It suggests it be used as a market one day a week where shops from the local town could set up a store and the post office and bank provide facilities. The report calls also for more experimentation with flexible transport systems such as dial-a-bus, post buses and voluntary car services.

Wheelchairs.

From Equipment for the Disabled, Mary Marlborough Lodge, Nuffield Orthopaedic Centre, Headington, Oxford.
Price £3.30 plus 80p post and packing.

THIS IS the fifth edition of *Wheelchairs.* It gives very useful information and illustrations of vehicles provided through the DHSS and privately, and has information, too on how to handle a chair. There are useful addresses, and data about mobility and VAT. Accessories are not forgotten either — all kinds, from lap desks to waterproof covers and pushing gloves.

Camping for the Disabled.

From Mobility Information Service, Copthorne Community Hall, Shelton Rd, Copthorne, Shrewsbury.
Price 30p.

THIS is a valuable new information leaflet on camping for disabled people from the Mobility Information Service.

DLF Music Advisory Service

ONE of the resource papers of interest to disabled musicians is:

MP7 "Music for One-handed Pianists", £1 plus postage from: Daphne Kennard, Music Adviser, DLF, 346 Kensington High Street, London W14.

The name of the publication was unfortunately incorrectly given in the last LINK.

'Friends often come and talk to me and tell me their troubles when they feel depressed. I like to feel I can help them . . .' from *I Use a Wheelchair,* a bright little booklet in the Althea series from Dinosaur books, (produced in cooperation with the Spastics Society).

It tries to put across to young children the point-of-view of someone in a wheelchair. It aims to help them understand the problems of disablement, and that although a child may be in a chair he can be a good friend and fun to be with.

Price 95p from bookshops or from The Spastics Society, 12 Park Crescent, London W1 (plus p and p).

Wanted Kitchen ideas

HAVE YOU any bright ideas for kitchens suitable for disabled people?

The Disabled Living Foundation is rewriting its popular book *'Kitchen Sense'* and would be glad to have contributions from individuals with details of specific problems and their own successful solution to them.

Much research has been undertaken nationally and regionally on the day-to-day needs of disabled people. Manufacturers, and study groups have researched and reported numerous new aids to home making.

The new book will follow the original format but also include additional material dealing with the specific needs of those with visual impairment and skin disorders. Sections on kitchen planning, suitable equipment, shopping, nutrition, safety and practical skills will form the main part of the book, while appendices on advisory bodies and resources will prove useful, too.

A separate handbook of tried and tested recipes may be published.

Please send any ideas you have to:
Mrs Gwen Conacher, DLF, 346 Kensington High Street, London W14 8NS.

New company aims to please

HILARY Gatfield known to so many LINK readers for her work with Down's Surgical over many years, has formed a new company to care for the needs of the disabled.

The company, SURGIFIT, has been formed with another professional, Pamela Spurrell.

SURGIFIT not only stocks an extensive range of stoma and incontinence appliances and aids to daily living, but also provides a comprehensive nursing service to give disabled clients and their relatives or friends help and advice in coming to terms with their disability.

Although based in the South, there are nurses serving other areas — Carol Oag in Scotland, Maureen Knight in Birmingham, and Anne Porter and Irene Reed in the South.

Situated next to Epsom Downs Station there are facilities including a consulting room and showrooms, with qualified staff available to give clients help and advice. Home visits can also be made in cases of need.

There are parking facilities at the showrooms, which have easy access for the disabled. Trains run at regular intervals from London via Sutton to Epsom Downs station, if necessary clients can be picked up at other neighbouring stations. Epsom town centre is about 1½ miles away.

SURGIFIT is run by qualified nurses who also hold the B.I.S.T. Diploma of Ostomy and Incontinence Appliance Fitting.

We would be happy to give advice and help to your patient on care of stomas or coping with the problems of incontinence.

We are able to:—

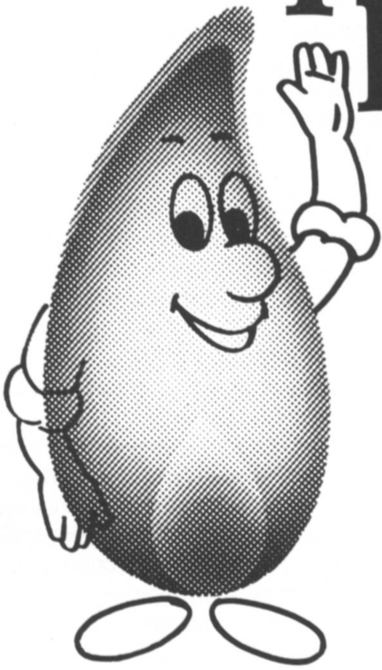
1) Dispense prescriptions for *ostomy and incontinence* products.
2) Fit appliances for children, male and female adult patients.
3) Catherisation — male and female patients. Intermittent catherisation taught. (Appropriate catheters stocked.)
4) Comprehensive range of pads and pants and protective bedding available.
5) Assessment of aids to daily living for disabled patients. *A comprehensive range of aids available.*
6) A private physiotherapy and occupational therapy service.
7) Seminars run for groups of interested staff.

Showrooms and offices are open from 10.00 a.m.-4.30 p.m. Ansaphone available out of office hours.

Appointments by request.

HILARY GATFIELD,
PAMELA SPURRELL

"Help yourself to the help you need."



British Gas offers a wide range of help to those who need it most—elderly and disabled people. If you have a disability—or have friends or relatives in need of help—here are some of the ways in which we can make life easier for you.

COOKING

For those with hand disabilities, many gas cookers can be fitted with special handles and controls. And remember, most new gas cookers need no matches to light them, because they have automatic ignition.

If you are confined to a wheelchair, you may find either a cooker with a waist-level grill or a built-in cooker helpful.

For those with failing sight or blindness, special braille thermostats are available for most gas cookers, together with braille cooking charts.

GAS FIRES

Many gas fires are available with easily accessible top controls, to save bending, and most fires light automatically when turned on.

And for those people with hand disabilities, a special tap adaptor may be fitted to a number of fires.

CENTRAL HEATING

Gas central heating needs very little attention and can be set to your own particular pattern of living. Time controls and room thermostats help to save gas and keep running costs down.

PAYING FOR GAS

The Code of Practice for the payment of domestic gas and electricity bills offers advice to customers who are unable to pay their fuel bills because of real hardship. Copies of the Code are available from gas showrooms and local offices, Citizens Advice Bureaux and other advice centres.

If you are blind, severely sick or disabled, you should tell us so that an acceptable method of payment may be agreed with you and so avoid possible disconnection.

Pre-payment gas meters can be re-positioned at a convenient height for disabled people, and special extended handles are available.

HOW TO HELP YOURSELF

Go to your local gas showroom. If you cannot go, contact the Home Service Adviser of your Gas Region, who will be happy to call on you at home and provide advice free of charge. (You'll find the address and telephone number in your local telephone directory under GAS).

MORE HELP

For information about other ways in which we can help—with safety and economy hints, for example, or with a choice of ways in which you can spread the cost of your gas more evenly throughout the year—contact your local Showroom.

BRITISH GAS

Conference spells out the need for freedom

FREEDOM was the keynote of the Spring Conference this year which was held for the second time at Goldsmiths' College in South London. Almost all the speakers whose topics ranged over housing, mobility and independence, expressed the importance of individual freedom for disabled people, and the chance to choose for themselves what they wanted from life.

Over 135 people attended the conference — members of local associations, ASBAH national and regional staff, professional workers, and more young LIFT members than ever before.

It was significant that there was more participation from disabled members than in previous years and evidence that they are starting to speak for themselves and to participate in activities such as ASBAH's independence training courses, to give their experience and time to help others.

The Conference hostess was Mrs Jean Black a member of ASBAH Executive and who helped to make the weekend such a success. The Lady Jean Mackenzie was unable to be at the Conference this year.

The chairmanship of the weekend was in the capable hands of Mr Dennis Bryant, Chairman of ASBAH's Executive. He said that when it came to talking about independence, we must remember that we are all interdependent, whether we are able-bodied or disabled.

"We all rely on someone else, and usually on a lot of people. The important thing is to get the right balance between interdependence and independence."

Variety is the spice of housing

THERE are an increasing number and variety of housing schemes and opportunities for independent living for disabled people all over the country, said Mr Charles Moore, Executive Director of John Grooms' Association.

Mr Moore and Mr A Plumpton, also from John Grooms, gave the Introductory Talk to the Conference, and emphasised the opportunities that now existed.

They said that things had come a long way since John Grooms opened the first house in 1867.

"In those days the disabled residents had to get up stairs by pulling themselves up on a rope, and get down by sliding down on their bottoms" said Mr Moore.

Nowadays there were opportunities to try out independent living. Mr Moore spoke of John Grooms' penthouse flat in London where a disabled person could live on his own for a short while in a big city environment. There were 'halfway house' opportunities, where a disabled person hired his own caring staff. One example of this in Derbyshire was where a young severely disabled man, Philip, had paid eight ladies to look after him. It was of considerable help that in Derbyshire, the authority paid a Domestic Allowance Assistance of £25 per week, over and above the Attendance Allowance, and this allowed Philip to pay for his care. Over the months Philip had managed to reduce the amount of care he needed, and therefore the amount he paid out. He had learned some of the advantages of being independent.

Mr Moore gave details, too, of a co-operative scheme where three disabled couples lived on the ground floor of a block of flats, and three able-bodied couples lived above and helped where necessary.

He said that John Grooms was in the process of completing a new £¾ million block of flats on the sea front at Southend for 17 single disabled residents, plus care staff.

Like other speakers at the Conference he stressed the importance of local associations and individuals taking action themselves. "Think about the kind of accommodation you need, and talk about it to everyone you can think of — your field worker, social worker. . . . Put your name on the housing list because in this way you establish you have a need and the authority can build up a picture of the needs of the disabled people in their area. Ask about housing associations working in your area, and put your name on their lists.

Mr Plumpton emphasises the importance of the right kind of housing. "The shape and quality of our lives is influenced by what we can do at home, and this is particularly important if one spends a lot of time there".

Not everyone wants to 'climb mountains'

A PLEA to professionals not to expect all disabled people to want to achieve independence and 'to climb Everest' was made by Mr Gordon Holloway, General Secretary of the Shaftesbury Society and one of the most dynamic speakers at the Conference.

"We as professionals feel that disabled people should be encouraged to achieve great independence. I am not sure that this is altogether right.

"I, personally, would not want to be expected to be always on top form, and a lot of disabled people get dispirited inside when more is expected of them than they want or are able to achieve. As professionals we must adapt. We mustn't forget that there are many people with spina bifida who can't climb mountains; they are probably people who wouldn't come to this Conference, or who don't like to speak out. We must be realistic, and not build up young people's expectations."

Mr Holloway conducted an opinion poll amongst those at the Conference. He divided people into four groups — disabled living independently; disabled living at home; parents; professionals with no direct emotional ties — and asked them to put in order of priority the following needs that they thought were important for the disabled: all modern conveniences in the home; freedom to make one's own choices, and mistakes; help and advice when necessary; other factors.

The group of disabled people living independently said they rated most highly the need for freedom. "For them this is fine. They have already proved they can cope with a minimum of help. But they mustn't make other

Continued on page 16.

'We don't want to conform to everyone else'

A SPEAKER who really made his mark at the Conference was Stephen Burton, a young man who is very severely disabled, is a qualified solicitor and works for Sheltered Housing for the Disabled (SHAD). Through his own determination Stephen has organised for himself the life he wants — an independent life in his own home, by relying on a team of volunteers who come in and see to his needs. His philosophy of life, which he gave at the Conference, is worth being read by everyone.

"One of the hardest basic facts to get across is that disabled people are not a homogeneous group. Each of us is quite different from the other. It is up to disabled people to get out and tell others this fact. . . ."

He referred to a popular advertisement for lemonade with a lot of bubbles bouncing into the lemonade bottle, with one large bubble staying outside because it was too big and didn't fit in.

"I maintain that we are the bubbles that are quite happy to stay on the outside. We don't want to conform to everyone else. Disabled people are all too often asked to conform to the system, and never the system to conform to us. And yet, I know no other area of life where this is so.

"We disabled people must start from the beginning and change the statutory authorities' perception of our needs. We must go out and tell people what we want."

Stephen then went on to make the case for disabled people to have real homes of their own choosing:

"The Englishman's home is indeed his castle; yet to the vast majority of severely disabled people having a house of their own is building castles in the air. Somehow, through no fault of their own this tiny minority represents that part of life that Society prefers not to see.

"In building their castles in the form of inaccessible large country estates our forfathers had no vision of what a useful piece of social apparatus they were installing. The elegance of yesterday's mansion marks to many severly disabled people the boundary of their very existence, and the seclusion of the past means the segregation of today.

"But, if we are to salvage what remains of IYDP from just being an exercise in public relations or an opportunity for a fund-raising cash bonanza, and transform it into a serious appreciation of the problems of disability, shouldn't we be just a little curious about the existence of these establishments? To sustain some degree of respectability, shouldn't we ascertain whether anybody wants to live there? Or is the real truth simply that we are afraid to press the matter hard just in case some of those people that we have successfully buried may be still alive! And who knows they may even choose to live next door. Heaven forbid!

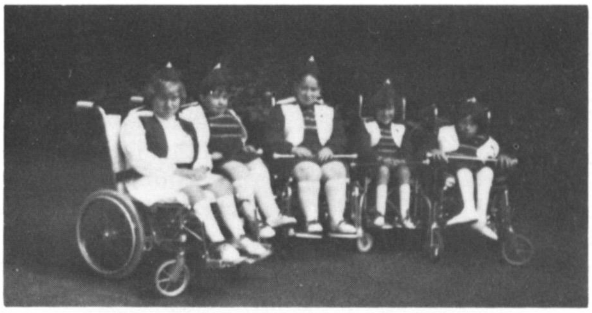
"We live in a society of supply and demand, but the severely disabled aren't very skilled in making demands from a society which teaches the fact that the very existence is a demand in itself. . . .

"As yet it is too early to expect from the severely disabled community 'a Bill of Rights' seeking to secure those fundamental freedoms which the able-bodied world takes for granted. The resident in a long-stay care institution has no roots, no community ties and thus no power base from which to register a voice. But the time will come when we have to face that challenge; and indeed very soon the magic principle — 'out of sight; out of mind' won't work and that curse will be broken.

"Meanwhile, the need to search for suitable alternatives to residential institutions is here, and in many ways the news is encouraging; Even now a whole range of community-based projects exist; for the most part pioneered by disabled people themselves.

"I'm confined to a wheelchair, quite unable to wash, dress or feed myself, but I can still slam my own front door, and the numbers like me are growing fast. So soon, the few will be many. This is not dream; this is no delusion. . . .

"Finally, may I deliver a message from the severely disabled community to those agencies who promote long stay residential and segegational care. The time will come when the need for the long stay institutionalisation of each individual will have to be proved; not on the basis of lack of alternative facilities, but medically, morally and legally. And unless the necessary financial resources are released and substantial investment is channelled into new concepts and ideas that are flowing from disabled people themselves, those once tame clients won't wait for you to listen. They will turn away. Then those spacious offices once occupied by the directors of large commercial charities will be as redundant as those large country mansions, once so successfully used for their client's segregation."



The five young baton twirlers of the Michelle-Aires Baton Troupe who performed at the opening of the Spring Conference — leader Julie Shaw, Marcel Caddick, Janet Barker, Andrea Barker and Jane Sheppard. They are all members of Warrington, and of Liverpool local associations.

They were brought together a year ago and coached by Michelle Snell, a member of the Rocketts, a baton troupe that has won the World Championships. She has introduced formations and routines that they can do, and can do well. They give displays at public gatherings — as long as they can perform on concrete or hard floor. The effort of pushing a chair over grass is too great, as the troupe has already discovered on more than one occasion.

Supporting the troupe are three mothers, Mrs Laura Sheppard, Barbara Barker and Margaret Shaw, known as 'housemothers' and Dave Caddick — 'housefather'.

The girls wear an eye-catching scarlet and white uniform, with decorated banners on the backs of their chairs, made by the mothers.

The troupe got off the ground with a donation from the Prince of Wales Fund, and since then fund-raising has continued apace.

It's hard work, but they feel it is worthwhile. They are after all the only troupe of their kind in the country.

You don't have to drive to be mobile

MOBILITY ADVISER for ASBAH Mrs Leonie Holgate, told young people not to feel that they have to drive. "You choose your own lifestyle, and there are other ways of being mobile other than driving. It is not a failure on your part if you can't drive."

She said that the introduction at the age of 16 of the provisional licence for disabled youngsters was a mixed blessing. There were some who were tempted to start at this age when really they weren't ready for it, often because they hadn't had the same experience of road situations, or traffic training like able-bodied youngsters of the same age.

For those who wished to learn she advised a full assessment to look at the physical aspects and the kind of car adaptations that would be needed. For those with hydrocephalus there could be difficulties of perception — knowing where objects were in space and in relation to each other. This would make it hard when driving to judge the distance or speed of another car, or the space between two vehicles. An experienced instructor who understood these difficulties might be able to help.

Mrs Holgate said that the British School of Motoring did give some assessment, and would tell you the kind of controls suitable for you and would fit them so long as you were able to pay.

She spoke in particular of the work at Banstead Place Mobility Centre — set up just over a year ago to provide a disabled person with a full assessment so he could find out as much about himself and his ability to drive before setting out to get a licence or paying for costly lessons.

Any disabled person could go there and get a very thorough assessment taking in physical and psychological aspects, and could test their reactions on a driving simulator, or in a converted car on the special track at Banstead.

"At the end of the day we have a pretty good idea if there are any problems" she said.

Mrs Holgate stressed, too, the financial responsibilities of owing a car. "Buying a car is not the end of the story. There are lessons, petrol, insurance, the cost of any damage, the cost of putting aside money for the next car. It really should be gone into very closely."

Wheelchairs provided another acceptable form of mobility for many people, she said, and it could be worth considering an electric chair which could make one much more mobile within the community.

"It means that you could get down to the local shops without being physically exhausted or dirty so that you enjoyed it when you got there."

She mentioned also other vehicles that could meet many different individual needs.

Taxis were another way of getting around and many disabled people used this form of transport successfully and regularly. Enquire, too, at the social services department to see if there are any concessionary cars or voluntary organisations running car schemes.

Hints and useful addresses:

Insurance: *Be sure to shop around as quotes could vary enormously. Be careful in going to a small firm specialising in insurance for the disabled as there could be problems if it came to making a claim. The advantage of leasing a car through Motability is that one can get insurance cover for only £69.*

Wheelchair battery insurance: *James, Yarrow, Young & Co, 327 Station Road, Harrow, Middx. Tel: 01-863 5577. For more details of this scheme contact MIS (address below).*

Useful book on driving for the disabled: *Motoring and Mobility for Disabled People by Ann Darnborough and Derek Kinrade. From RADAR, 25 Mortimer Street, London W1N 8AB.*

Useful organisations: *The Disabled Drivers' Association and Disabled Drivers' Motor Club have local branches who could give advice and possibly help with driving practice. Second hand cars are advertised in the DDMC's magazine.*

Motoring Information Service: *Mr David Griffiths, MIS, Copthorne Community Hall, Shelton Road, Shrewsbury S23 8TD. Tel: 0743 68383. This is an organisation building up a lot of useful information about driving matters.*

Last, but not least: ASBAH's Mobility Adviser, Mrs Leonie Holgate, Banstead Place, Park Road, Banstead, Surrey. Write to her or telephone her on Thursdays (9.30 am-3.30 pm) Burgh Heath 56222. If you'd like an appointment to spend a day at the Mobility Centre for assessment contact Mrs Morigue Cornwell at Banstead (address above). Mrs. Holgate is happy to discuss *all* aspects of mobility with any disabled person — not just driving, but also wheelchairs and other vehicles.

'Not everyone wants to climb mountains'
(Cont. from p. 14)

disabled people feel inadequate if they don't live on the summit of this achievement" said Mr Holloway.

This group also rated highly the knowledge that help was around if needed, whereas those disabled people still living at home put this way down their list of priorities. "This group still living at home doesn't yet realise how important ready access to help can be for those living independently. It could spell disaster if they leapt out of the care of their home, and tried to shake off all help. Take advice from those who have already gone before".

Parents thought that having all modern and adapted conveniences in the home the most important need for a disabled person. "It's all too easy if you are young and still living at home to underestimate the importance of these" said Mr Holloway.

He said that some people do need and want care, do want a more modest level of achievement and may be quite content to live with their families if they had a good relationship there. Their wishes must be respected.

"We at the Shaftesbury Society and in conjunction with others are trying to provide a complete range of accommodation and care and I must stress the importance of building housing right in the community itself."

WATCH OUT FOR MORE CONFERENCE NEWS IN THE NEXT LINK.

Making friends — the LIFT way

THE IMPORTANCE of friendships came out strongly and a number of speakers made the point that LIFT’s Young Volunteer Scheme was proving to be a good way of young able-bodied and disabled people making friends.

Paul Cooper who runs LIFT said that although one might be ‘free’, or one might have learnt to be independent these weren’t enough, if one was still lonely.

‘‘Most of the disabled people I know either live at home or on their own, and a major problem they all face at some time is loneliness. . . .’’

‘‘Our primary aim on the volunteer scheme is to get LIFT members into groups — and the goal is to stay together. Take the Bucks. LIFT group, the average age is 16 — ie 5th form — they are just about to leave school. Things have been relatively easy up to now. They have seen their friends most days. But what happens now? In the transition phase between school kid and adult, do these people lose touch with each other because they haven’t learnt to drive or their parents are busy?

‘‘The volunteer scheme is trying to plug the gap so that disabled teenagers who have friends will become adults with friends. Disabled people need friends — not just other disabled people but able-bodied friends too. That’s why we have volunteers in the LIFT groups.

‘‘Disabled people need to get into the able-bodied world, and the able-bodied need to learn about the disabled, not just patronise them, or go numb when they see a wheelchair. LIFT needs to expand. Members are scattered. If LIFT is not to stand still, members must discover a sense of identity with each other and with us. I think the Volunteer Scheme is a way of doing it and I would be willing to help start up a group in your area.’’

Linda King, an able-bodied volunteer, and Lisa Cain a disabled member of the Essex LIFT group talked about their experiences:

Linda became a volunteer after Paul visited her school about a year ago to give a talk.

‘‘I went along to the talk to get out of an English lesson! The first LIFT meeting was a disco and I was terrified about what to expect. However, once I was there I had a great time and I was really looking forward to the next meeting. I have learnt a lot about other people and also about myself, and to be more outgoing — I’ll talk to anyone now.

‘‘As a volunteer I do very little work — I push the odd wheelchair up a kerb, but that’s about it really. Sometimes I get the feeling at the end of a meeting that I have enjoyed it more than the LIFT members.’’

Lisa outlined some of the things the group have done. ‘‘We have fortnightly meetings. We have had discos, and we have been to the zoo. One of the best things we did was to go shopping just before Christmas. I thought this was really great. It was the first time I have ever been to buy my mum a Christmas present without her standing at the other side of the shop. This may not sound very exciting, if you are able-bodied but for me it was an achievement.’’

For more information contact Paul Cooper or Vivien Harper at the LIFT Office, ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. Tel: 01-388 1382.

Looking surprisingly happy, considering the chore they are doing — Zena (left) and Sian — two young people who recently had a taste of doing things for themselves at an independence training course at Five Oaks. Sian spoke at the Conference about the opportunity she has to move into a flat of her own (see below).

Photo: Bradford Telegraph and Argus.

Newport scheme will ‘bridge the gap’

A TWO STOREY block of flats that is being built for disabled people in Newport has come about through the partnership of ASBAH and the Family Care Housing Association which has put up the money for the project.

The two ASBAH fieldworkers involved with the scheme are Mrs Joyce Hodge and Mr Tom Davies and both of them told the conference about the flats — four one bedroomed flats, and four with two bedrooms, with wheelchair residents on the ground floor.

‘‘We feel that this project is a step forward towards building the difficult bridge between the overprotectiveness of the family and the full independence of the community. . . . Our aim will be to assist the residents through the transition. We shall try to avoid being overprotective, but at the same time be available for advice and consultation’’ said Tom Davies. Sian Townsend from South Wales valley town, Blaind, near Newport, is the first candidate for a flat.

‘‘At present she is living at home with her parents and her brother’’ said Joyce Hodge ‘‘but like most young people of her age she’d like to branch out on her own. In view of this she has just attended an independence course at Five Oaks.

Sian spoke at the conference: ‘‘Following my two weeks independence training in preparation for living on my own there is only one real problem that comes to mind — the feeling of isolation — of not being able to say ‘Mam, do so and so’ or ‘Mam give me a hand with this please’.

‘‘That’s where Joyce and Tom come in. It is going to take a while for me to realise that I, in the nicest possible sense, don’t really need mam around as long as I know there is someone on the other end of the phone who will always be there to give reassurance, advice and if necessary a bit of help here and there, especially for the first, shall we say, six months to a year. Apart from that I don’t really need them either.’’

Fashion Services for the Disabled try to meet the needs of each individual

Comfortable clothes for 'a more beautiful you'

"WHEN we know we look attractive, we feel good, we sit better, we go out and meet people, we have confidence in ourselves, we attract attention for the right reasons."

This is the philosophy behind Fashion Services for the Disabled — a research project being run by Mrs Nellie Thornton the Project Director from workshops in Shipley, West Yorkshire.

Her talk attracted much attention — not least because of the eye-catching clothing that she had brought with her, some of which was modelled by young people at the conference.

She said "We are a project funded by the government looking at the clothing problems and needs of disabled people, and designing and making garments which are fashionable, flattering, a good fit and which take into account the needs of the individual and make them as independent as possible. Fashion isn't for 'them'. It's for everyone to enjoy and that includes you. "If you feel uncomfortable and dowdy you probably decline to go out. Life passes a lot of disabled people by because they don't feel they have the right clothes and they stay at home."

Common clothing problems included garments that only fitted round the chest, clothing that clearly belonged to a different age group, trouser waists that dipped at the back, too small necks on t-shirts and jumpers, trousers worn out through caliper rub, cold limbs.

Mrs Thornton runs courses at Shipley for disabled people — of both sexes — for mothers, and care staff. "We help you to choose the styles and the colours that work for you. We measure you, make basic patterns and show you how to alter them to the style you choose, and to make up the garment. There will be care students or dress students working with you to give you a helping hand with cutting out, or with any bits you find difficult. . . . If you've never sewn before, it doesn't matter.

"At the end of the course not only do we have a more beautiful you, but you have a great feeling of achievement. You can save a lot of money making your own clothes, and perhaps even make money sewing for others."

Mrs Thornton mentioned the course being held at the end of the month (April) at Five Oaks in conjuction with ASBAH and being attended by a number of young people with spina bifida and hydrocephalus.

Fashion Services for the Disabled try out new suitable fabrics, badger manufacturers into making non-standard sizes and interest industry in producing the kind of garments needed by disabled people. The workshops also produce one off garments individually designed.

One manufacturer has already come forward and is working on a very attractive range of leisurewear garments to fit able-bodied people and to include the needs of the disabled. "They are eye-catching fashionable styles that anyone would love to wear" said Mrs Thornton. A couple of prototypes of the garments were modelled and attracted much favourable attention (LINK will let you know when the styles are on the market).

"We are interested in any clothing problems you have" said Mrs Thornton. "We will run special courses if you can get a group together, and we hope to see lots of you in Yorkshire in the not too distant future".

For more information contact Mrs N Thornton, Fashion Services for the Disabled, Units B270-B320, Saltaire Workshops, Ashley Lane, Shipley, West Yorkshire BD17 7SR. Tel: Bradford 597487.

The right to live in 'the house next door'

THE NEED for mentally handicapped people to be allowed to live in ordinary houses as part of ordinary communities was emphasised at the Conference by Mr Harry Neal, Director of Residential Services for Mencap.

He said the situation today was vastly better then in the past when those with mental handicaps were classed as lunatics to be hidden away in asylums. But there were still rules and regulations which made it very difficult for them to assimilate into the community.

He said that under the 1959 Mental Health Act it was usually necessary to apply for planning permission as 'a hostel for the mentally disordered', even if this was to be only slightly bigger than an average family with about eight people living in an ordinary-looking house.

"Planning permission means registration which leads to all kinds of impositions — inspecting officials, smoke detectors, fire regulations — all kinds of rules that none of would dream of living with. Why do we need to ask permission to live in a residential area? A group of six office workers wouldn't have to ask permission to share a house. Are six mentally handicapped adults untidier or noisier than six office workers?"

He explained that MENCAP now had about 500 local branches thoughout the country, able to offer friendship to people when a new house was opened.

"Our most constant problem is to get parents to accept that their children — even if they are in their 30's — can cope away from home."

He echoed the view of others that independence training was important before someone was expected to live on his own. He felt that equally important as this was for people to get to know each other beforehand if they were to be expected to live in some kind of group situation. They must be compatible. It was no good, he said, having people with a good mixture and balance of skills, if the individuals didn't like each other.

He stressed that the move out of residential care into independent living must come at the request of the person himself.

"We can put the idea into their heads, but they must express the wish to move. It mustn't be just what the professional wants."

Coping with Incontinence

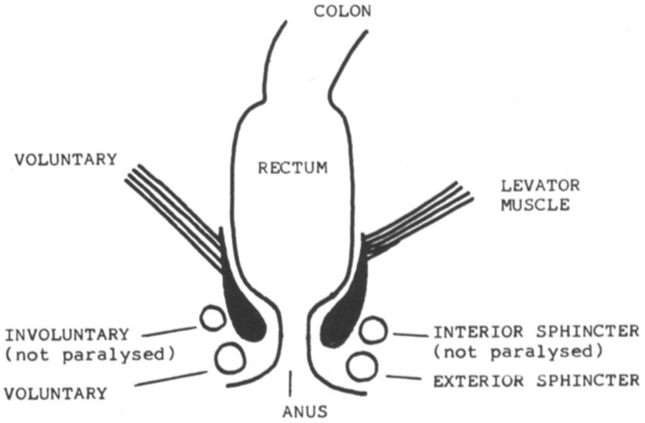
RECENTLY, I was invited to a parents' meeting in a Special School in the West Midlands to discuss bowel incontinence and management. Sadly, during our discussion it became obvious that this vitally important subject was often overlooked by the caring professionals. As a result, the majority of parents were 'feeling in the dark', struggling to find a satisfactory bowel management programme on their own.

ASBAH is concerned that a young person with spina bifida becomes as independent as possible and attains his full potential despite the limitations of his physical handicap.

There are many physical, psychological and social implications of unsatisfactorily managed bowel and urinary incontinence, and it can greatly minimise the possibility for personal development and independence.

Equally, the method of management chosen should be geared so that the young person can manage it himself as far as is possible.

How do bowels work?

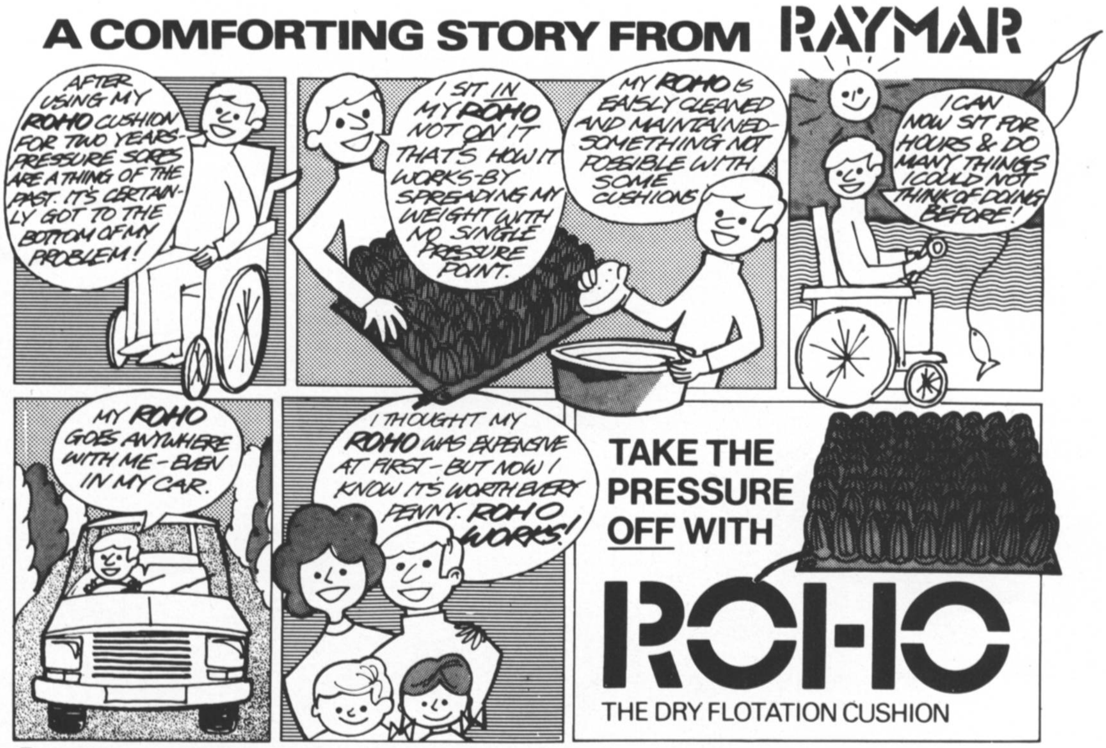


As you can see in the diagram, three pairs of muscles control the anal canal between the rectum and the anus. When a person with an intact nerve supply feels the sensation of a stool in the rectum he can contract these muscles and prevent the stool contents being passed until it is socially appropriate.

When the spinal cord is damaged, messages to and from the voluntary muscles in the bowel do not register in the brain. Due to lack of sensation, the child cannot tell when the bowel is full and requires emptying. Stools therefore remain in the bowel much longer than usual and may stretch and distend it. The passage of stools along the bowel is also sluggish and so more water is absorbed than normal, causing constipation. Hard, dry stools take even longer to move out which may lead to impaction (a blockage of stool). Sometimes liquid stool flows around the blockage appearing like diarrhoea when the problem is just the opposite.

It is very important to realise that the involuntary pair of muscles in the anal sphincter still operate as their nerves do not run up the spinal cord to the brain and are

Continued on page 24



The fact that you can't see it may be the least of its benefits.

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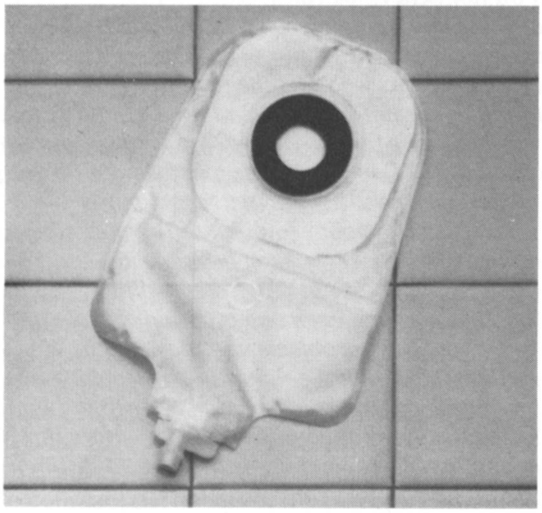

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THE ARTICLE about Number Work and Mathematics and the spina bifida/hydrocephalic child (LINK 84, Jan/Feb) brought in a number of letters from readers thanking us for printing the article and saying how helpful it had been. It also provoked much more detailed comment from Mrs Peters and Miss C J Peters of Guildford, Surrey, which we carry below:

Did survey on 'Number Work' add up to complete picture?

I WAS DISTURBED to read the article about Mathematics and the Spina Bifida/Hydrocephalic child, LINK, Jan/Feb. Surveys like these, based on a selected group, need careful study and I think they do a disservice to our children. The general public absorbs only the broad information and now they are being told spina bifida and hydrocephalic children may have difficulties with mathematics.

This was my initial reaction and then I saw here was an opportunity to offer constructive criticism. I believe that our children have differing abilities and that we should not accept 'blanket' descriptions of their physical or mental state. I would like to see the Association carry out a survey of the educational achievements of those between the ages of sixteen and twenty-five. Throughout the country the average number of 'O' levels per person is between one and two, our daughter has twelve 'O', three 'A' levels and a BSc(Hons) degree and we know she is not unique within the Association. I think a survey might give us quite a different view of learning ability (our daughter's 'A' levels include Physics and Mathematics).

In the past my husband and I have been reluctant to say too much about our daughter. We feared we might give false hope to those less fortunate than us. Now I think we should give encouragement to those who struggle to help their children.

Nothing is gained by accepting the children 'for what they are'. Almost all can be helped to improve their standard. I was about to write 'we were lucky' and then I thought about it and have to say that 'luck' did not come into it. We pleaded and fought to have our daughter educated with able-bodied children, we encouraged her to swim, to play the piano and the flute and to take speech training lessons and art classes. These activities cost time and money and in our earlier years it was a struggle financially (no attendance or mobility allowance then) and there was another young child who needed attention. We asked for major operations to be performed in the school holidays in order to lessen the schooling loss and the hospitals always tried to help.

All this requires perseverance by both the parents and the child but it has its rewards. We were delighted by all the achievements but we had also helped to correct some of the weaknesses caused by the spina bifida. The swimming and the flute playing helped to improve her breathing, the piano and the art gave her better co-ordination and the speech training helped the 'thin' voice to project.

Our daughter is now working towards a doctorate in hearing research and I am enclosing her scientific assessment of the article (next page). She had felt victim of this type of survey in the past and now never states that she has spina bifida, only that she is confined to a wheelchair. She has found people have a stereotype idea of a person with spina bifida to which she does not conform. How many do?

MRS D PETERS, Guildford, Surrey

BARBARA NEWMAN, ASBAH's Educational, Training and Employment Officer writes:

With regard to Mrs Peter's suggestion that we carry out a survey, I feel that there are so many factors affecting the acquiring of O levels (as opposed to CSEs) and therefore, A levels, that a purely statistical survey would not be very helpful. I do understand her feeling that we should highlight young people who have achieved academic success, but it is my belief that LINK has always had a policy of doing this.

I do not believe we can ignore the severe difficulties that those children with spina bifida and hydrocephalus have in learning. In fact, most of the enquiries I receive are from parents who feel their children's learning difficulties are not being taken into account by teachers. It was because of this feeling in the further education sector that the Banstead Place and Derwen Projects were commissioned by ASBAH (see report pages 4/5 . . .).

It is ASBAH's policy to point out, in describing the learning difficulties of young people with hydrocephalus, that not all *of them will have* all *the difficulties and that each one is an individual and may have few or many problems and may well be able to overcome them with the right kind of teaching help. Of course children with spina bifida only will not be affected by these subtle difficulties any more than the general population, and it is important to distinguish between the groups in any survey.*

More on next page

Some 'problems' with the survey

I READ WITH interest your article on number work and mathematics in spina bifida and hydrocephalus children.

The study compared such children attending special schools in Derbyshire, Leicestershire and Nottinghamshire with non-disabled children attending normal schools. The spina bifida and hydrocephalus children had a very wide IQ range (49-130) and for study of this kind it would be important that non-disabled children were matched in some way with this sample, otherwise the study would be comparing children of widely differing IQ which could affect the analysis of the data. A similar problem is that of differing social and cultural background. The authors do not specifically state that these factors were controlled for, but even assuming they were, the study still has several problems inherent in it.

Perhaps the most obvious problem is that of a comparison between children at normal and special schools. There are two facets to this.

- There are differences in educational methods between normal and special schools and these almost certainly lead to differences in educational attainment between children of equal ability. This factor could have been controlled for by comparing spina bifida and hydrocephalus children in normal schools with their non-disabled peers, or by making a comparative study of spina bifida and hydrocephalus children in special schools with other physically disabled children in special schools to compare the effects of a particular disability on learning with those which are solely due to the kind of education being received.

The first method has an inherent problem, in that it would probably take in only those spina bifida and hydrocephalus children with mild disabilities, but the second method would be valid in that it would allow a comparison to be made between the effects of special schooling on disabled children in general and on spina bifida and hydrocephalus children in particular.

- The second point is that children in special schools are more likely to have to spend large amounts of time in hospital during the course of their education which normal children do not. This factor was mentioned briefly in the introduction to this paper, but I feel it should have been given more consideration.

An important fact to remember when reading this article is that in science, nothing is ever proved — it is either supported or shown to be wrong. In the light of this, and my points about the study itself, I would like to go back to the suggestions made in its introduction about methods of education. Assuming that this study may have shown that there can be impairment of development of mathematical ability in children with spina bifida, I suggest this finding could cause a great loss of realisation of true potential among many children for whom, I suggest, retardation is due not to their disabilities but to their background and lack of educational opportunities during, for instance, periods in hospital. I propose, therefore, that the most important lesson to be learned from this study is that, remedial teaching of mathematical (and other) concepts may be necessary to counter the disadvantages of educational deprivation as well as physical handicap.

C. J. PETERS (BSc)
Dept Psychology, University of Reading

'Blanket' descriptions give wrong idea

LINK gave the authors of 'Number Work and Mathematics' — Dr David Green, and Dr Vernon Parfitt — the opportunity to comment on Miss Peter's article. Here is their reply:

We were interested to read Miss Peters' comments and rather dismayed that she has interpreted our work in a way very far from our intentions. Perhaps our article has provided the opportunity for Miss Peters to express her own views, which she has done very clearly.

We do not feel that matching *of children would have been appropriate in this research (even had it been feasible, which seems a naive assumption). We looked at a large number of spina bifida children in one geographical area. We did not pick one out here and one out there, but tested all the children (with spina bifida/hydrocephalus) from four special schools (except one blind child).*

Such comparisons as we did make were mainly with the reported research results of others who have followed up Piaget's seminal work on a large scale, and also with some of our subjects repeating the tests three years later.

Miss Peters also raises the 'problem' of 'different social and cultural backgrounds'. We see no problem. We simply reported on those children attending four East Midlands schools for the physically handicapped. This produced a very wide distribution of test marks (eg IQ from 49 to 130, mean 81). We fail to see how this amounts to a blanket condemnation — quite the reverse. However, it does indicate a lower average performance than the population as a whole, but that is hardly surprising. All manner of social, psychological, educational and medical factors combine to influence the results. We would, naturally, endorse Miss Peters' warning against the uncritical acceptance of reported findings. However, we would also warn against remarks such as 'in science nothing is proven . . .' which provide an excuse for prejudice.

We are most certainly in agreement with Miss Peters' closing paragraphs where she advocates a positive attitude and positive intervention — indeed we recommend this in our second article (LINK 85, March/April last two paragraphs).

In closing, it is appropriate to point out that very few of us achieve our full potential. Children in normal state schools just as much as those in special schools can benefit from greater active interest and informed encouragement from parents and teachers.

DAVID GREEN, V. PARFITT

Message of hope lies behind the sad story of PHAB award

TWO YOUNG men, both members of St George's PHAB Club in Harrogate have died suddenly in the last 18 months.

A special fund has been set up and two trophies have been given to the Club in memory of one of them, Richard Merrick, an able-bodied member. The other member, Thomas Palmer who had spina bifida, was awarded one of the trophies, but died before he could receive it.

It's a sad and moving story, but in some ways an encouraging story too. The Leader of St George's PHAB, Mrs Iris Linford, has written to LINK:

RICHARD MERRICK was an able-bodied young man who died after a motor cycle accident in February 1982. He was test driving the machine after servicing it for his best friend. He was 19, and a member of our club, among other interests.

His parents requested that there be no floral tributes, but that the money should come to the club. A fund was set up, which will send young people on courses which would otherwise be prohibitive because of costs.

In addition it was decided that two trophies should be awarded yearly together with a small monetary prize, to members who, in the opinion of the club leaders, had made some notable contribution to club life and shown some personal development worthy of note.

This sprang from Richard's own development, for like many of his age, he had gone through a period of rebelling against the system, and was finally using his energies for the good of others.

This year the awards went to Thomas Palmer who had spina bifida, and Alison Mace, an able-bodied girl.

Thomas was rather retiring by nature, but underneath there was always the yearning to 'get into the ring'. He died, quite suddenly last June, leaving us all shocked and empty. He had been with the club camping and was anticipating going again this year. He adored to dance, particulary to 'heavy rock'.

We had already decided to give him the Award, as soon as it was created. In the event, we had to wait to tell his parents, until the presentation was imminent in February of this year, and they accepted it posthumously on his behalf.

The second award went to a girl about whom we almost forgot. She was always there, behind the coffee bar, part of the team whenever we had an event, looking to the needs of the less able handicapped, and we took it all for granted. Her quiet dedicated approach was a lesson to some of the more 'verbal' members of the club who say much and do little.

The criteria for the awards are flexible. What seems to have happened is that some members are responding to the idea of having their name on something and are trying hard for next time. If nothing else they are something positive to aim for. In a club where we have had five deaths — all members and all in the prime of life — we have at all costs to think positively and make our meetings very worthwhile.

Coping with incontinence (Continued)

therefore undamaged. These nerve impulses and muscle actions are completely ineffective if the bowel is over-full and distended. However, when given the chance and the constipation problem is eliminated and prevented from recurring, these muscles can allow the child to gain control over his bowel actions.

Prevention of constipation

First of all, one should assess and adjust the diet as this has a tremendous effect on the bowel. Avoid those foods which tend to produce constipation, eg eggs, bananas, carrots and rice cereals. It must be remembered that how our bodies react to certain foods is an individual thing. Food that softens one person's stools may constipate another.

Foods that contain fibre are very important in bowel management programmes. As fibre is not broken down during digestion, its bulk stimulates the bowel to move and this helps push the stool through the bowel faster. It also helps keep more water in the bowel, keeping the stool softer and easier to move. Some of the foods with high fibre are raw unpeeled fruits and vegetables; dried or stewed fruits; prunes, etc; whole grain cereals and bread; bran, oatmeal and wheat germ. Drinking lots of fluids such as water, juices, etc will also help keep the stools softer. Increased physical activity and scheduled toileting also prevent constipation.

Managing the diet is the most important aspect in preventing constipation, but even so it is still possible for your child to have constipated stools. Some reasons may be: lack of exercise; poor appetite; medication. If the dietary management has not been successful, or if there are additional reasons he is constipated, stool softeners may be used. Stool softeners, eg Senokot, are preparations which are given by mouth to act on the bowel to soften the stool. When it is appropriate to use such a compound, what the dose should be and how often you should give it has to be carefully considered and altered according to the results! Initially, if the child is impacted or has very hard stools, enemas may be used to clear the bowel. This should not be used as a regular routine merely to get rid of very hard stools.

Stimulation or massage may be required on the abdomen, or around the anus itself to stimulate bowel movement. The child can be taught to do this himself.

If constipation can be avoided, and a successful routine adhered to, the child will gain freedom from pads and pants giving a further degree of personal and social confidence.

A tremendous amount has previously been written on this subject and a great deal of valuable information has been collected in the national office. If you would like to talk to one of the Disabled Living Advisers about this problem or would like more detailed information on bowel habit programmes other families have found successful, please contact the Disabled Living Adviser at National Office.

MARY SMALL,
Disabled Living Adviser ASBAH

HMS Illustrious sails to ASBAH's aid

HMS ILLUSTRIOUS, Britains newest warship, which was commissioned on 20 June 1982 and sailed for the Falklands shortly afterwards, has adopted ASBAH as one of the two charities which the ship's company will be supporting.

I had the good fortune to be invited on board recently to meet the Executive Officer, Commander John Tolhurst, RN, and together we discussed the ways in which the officers and men might be prepared to help our Association. Ideas were flying thick and fast and despite the slight apprehension of the the Commander, it is anticipated that a Yard of Ale Drinking contest will take place during the ship's visit to The Tyne in May. On a more energetic note, plans are already in hand to field teams from the ship to participate in Mountain Express on 20 August. Commander Tolhurst assured me that other plans would be hatched in liaison with the Welfare Committee and we are all eagerly anticipating an opportunity to go back on board to thank, and congratulate, the 1,000 officers and men on their support of ASBAH.

★ ★ ★ ★

MOVING FROM the glamour of Britain's Senior Service to the glitter of show business, I am happy to report that the re-creation of the war time Stage Door Canteen, which was staged by Barry J. Mishon at The Lyceum Ballroom on 6 March, proved to be a tremendous success at every level, encompassing considerable press coverage, a most enjoyable and entertaining evening and a substantial profit!

More than forty stars of stage and screen were present, performing in cabaret, being photographed with out guests, waiting at tables and being hired as taxi dancers and everybody entered into the spirit of the event magnificently. Most of the people attending had taken the trouble to dress up in military uniforms or in forties style civilian wear and I have to admit to a tinge of envy when Diana Sheridan told me that she was wearing her original service uniform which still fitted perfectly!

Shaw Taylor, Barry Cryer and Don Moss, in addition to being so generous with their support during the planning stages were superb in the shared marathon of compering the evening, which ran from 6.30 until midnight and our departing guests all declared themselves most anxious to be informed of the date when the event will be repeated.

★ ★ ★ ★

IT IS CERTAINLY satisfying when one can capitalise and consolidate on past successes and this is definitely the case as regards the second Chatathon, which at the time of writing is in the final planning stages and is to be held at the Inter-Continental Hotel on 16 and 17 April, to find the Conversationalist of the Year 1983.

Sixty exponents of the gentle art of conversation will gather to talk their way through a twelve hour marathon on the 16th and selected quarter-finalists will return on Sunday, 17th to be put through their paces under the watchful eyes of our judges, Willie Rushton, Gyles Brandreth, Dr. L. L. Ware, founder of MENSA, and Mr. Derek Coltman, our reigning champion. Those who know me will not be surprised to learn that twelve hours struck me as a bit tame and I will therefore be attempting a distance record of 34 hours from the moment the contest starts and through the night to the point at which the winner is announced. Five noble people have 'volunteered' to partner me through this attempt to establish a record and who knows, perhaps some fundraising ideas may emerge during the course of discussions!

★ ★ ★ ★

STILL AT the Inter-Continental Hotel, the staff of which are proving to be most generous to our cause, we will be promoting the Crown Jewel Ball on 11 May. Mr Harry Winson, the internationally acclaimed American jeweller will be flying in a collection of jewels. Due to a press embargo, I cannot at this stage reveal the full value of the jewels, but can hint that they are sumptuous.

Sister Caroline Nathan organising some of the young patients at the Leon Gillis Unit at Queen Mary's Hospital, Roehampton, in the job of bundling up stamps. (See story on this page.)

OF COURSE, major promotional events are only one aspect of the full spectrum of fundraising which is necessary to finance the activities of ASBAH and without the support of many thousands of people all over the country, who work with such dedication to produce contributions for us, the Association could not survive. Just such a wonderful friend is Sister Caroline Nathan of the Leon Gillis Unit at Queen Mary's Hospital, Roehampton, who has worked tirelessly to organise the staff of the unit, patients and their parents, in fact almost the entire hospital, in collecting, trimming and bundling used stamps, in order to raise funds to finance research.

Our picture shows them at work. Ann Gosling went along to meet everybody and to collect the fruits of their labour and was delighted to be told that the good work would continue and that ASBAH would always have a place in their hearts.

NOW THAT the new fiscal year is upon us, with a target of more than £¾ million to reach, the Appeals staff are renewing and redoubling their efforts to ensure that the grim forebodings of George Orwell will not apply to ASBAH and that we will steam into 1984 with all guns blazing and flags flying, perhaps not so unlike HMS Illustrious!

JUDY KAY, Director of Appeals

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Asian language translations of a Fact Sheet about spina bifida and hydrocephalus and ASBAH's work are available free from national office. Translations into Bengali, Gujarati, Hindu, Punjabi and Urdu. Welsh language sheets are now ready too. All available from ASBAH. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 15p per booklet.

Scottish Spina Bifida Association Booklets

Growing up with Spina Bifida	35p
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both by O. R. Nettles, McSP, ONC.
Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

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The Appeals Dept. carries a range of fund-raising and publicity items, i.e. posters, pens, key rings, games. Send for list and order form.

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