



Link

Association for Spina Bifida and Hydrocephalus/ASBAH 20p

Jan/Feb 83



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Benefits**

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Association for Spina Bifida
and Hydrocephalus/ASBAH

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Tavistock Square,
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Tel: 01-388 1382/5

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

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Challenging the 'stereotypes' about disablement

The winner of the 1982 Harding Award for outstanding work for the disabled was Mr Selwyn Goldsmith, an architect whose pioneering work on designing for the disabled has gained international recognition. He is the author of 'Designing for the Disabled', and has been directly concerned with the formulation of official guidelines for access to public buildings, and housing design. A particular achievement has been to show how ordinary housing can meet the needs of disabled people at virtually no extra cost.

Selwyn Goldsmith, disabled from polio since 1956, is professional adviser in the Department of the Environment Housing Development Directorate. In his address of acceptance of the Award, he questioned many of the fashionable views about discrimination against the disabled, and expressed scepticism about certain disabled rights movements and the demand for anti-discrimination laws. Compared with other countries, he said, there is in fact very little discrimination against disabled people in England.

Selwyn Goldsmith was speaking on his own behalf. He said:

IT IS a sad curiosity that the disabled field—what I tend to call the cripple patch—has attracted so little good academic exploration. Since there is no solid bank of empirical evidence, stereotypes are nurtured: that disabled people are socially oppressed; that they are deliberately segregated by an uncaring society from the busy world; that they are perceived as inferior and second-rate; that there is widespread discrimination against them; that they are treated in a patronising and condescending fashion.

Are these complaints genuinely valid? We have to say that we honestly don't know. Nor can we say that the counter-stereotypes are valid, for example that all disabled people want to be "independent"; to be "integrated", and to be treated "as normal".

My contention, having looked at a variety of other national products available across the world, is that, from a disabled consumer viewpoint, England is a best buy. Most importantly, I submit, there is, relatively and absolutely, little discrimination against disabled people in England. To those who are sceptical, try experiencing, for example, what Japan or Australia have to offer. But, affected by the guilt and discomfort which disablement evokes, the English readily chastise themselves, and the belief that there is widespread discrimination against disabled people is entrenched.

By discrimination against disabled people, I mean unfavourable and unwarranted treatment which stems from nasty attitudes. I do not mean access difficulties caused by physical obstacles—in public buildings and public transport, for example—which are an inevitable outcome of the interaction between human beings and the artefacts humanity constructs for its survival and well-being, and which, while they may be alleviated by technical (and perhaps expensive) prescription, can never be entirely eliminated.'

If we were to have legislation prohibiting discrimination against disabled people, we would need to devise regulations to proscribe unlawful negative discrimination, while at the same time sustaining

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Front Cover: Deep concentration on the face of this young girl joining in a session of mime run by Gina Leveté. See review of Gina's book on page 12. Photo reproduced from *No Handicap to Dance*.

While every care is taken to ensure accuracy of information published in LINK the publishers can accept no liability. Opinions expressed in articles are not necessarily those of ASBAH.

Study days prove success

THERE WAS an overwhelming response to ASBAH's first Study Day in November, held at Banstead Place, Surrey. Initially about 40 people were expected. In fact, over 100 attended, and they went away full of enthusiasm.

It was primarily a Study Day for nurses and care staff in ordinary schools. The medical conditions of spina bifida and hydrocephalus were explained, as well as current methods of incontinence management.

There was a session on the learning and perceptual problems of hydrocephalic students, and another on the organisation of individual personal care programmes, as well as other talks and discussions to aid and advise those attending the Day. One point emphasised was the need for staff in ordinary and special schools to work together locally.

The November Study Day was for staff in some southern counties, and it is hoped to run similar days in other parts of the country.

Another special day organised by ASBAH at the end of the year concentrated much more on the educational needs of young people with spina bifida and hydrocephalus. The Day Conference held at the Frederick Holmes School in Hull in November was attended by over 40 people from Hull, North Yorkshire and Humberside.

... and the next subject is ...

AN IMPORTANT Study Day to look at the effects of hydrocephalus on vocational and pre-vocational training is to be held by ASBAH very shortly—February 17, at the Thomas Coram Foundation in Brunswick Square, London. Full details have been widely circulated, but if anyone would like to have information about the Day they should contact National ASBAH as soon as possible.

The Study Day will look at the results and implications of two ASBAH research projects—by Mrs Hazel Benner and Leonie



The two presenters of ITV's LINK programme—Kevin Mulhern and Rosalie Wilkins.

Holgate—into the problems faced by young people with hydrocephalus at school, and more particularly when they leave school and enter the world of further education and training and try to make a future for themselves. Delegates will get bound copies of the research reports on the day.

It is likely to be of special interest to those in colleges of further education, and the careers service who have had little experience of young people with spina bifida and hydrocephalus.

Concentrating on Care

PERSONAL Care and Management Problems of Children and Young Adults with Spina Bifida and Hydrocephalus is the title of a special course, 28 February-3 March, being organised by ASBAH and Castle Priory College, at Priory Castle at Wallingford, in Oxfordshire.

It is an in depth course for nursing and care staff from ordinary and special schools, residential establishments, community and day centres.

Although it is a residential course it will be possible for local people to attend on a daily basis, or to register for just one day.

Details from Rosemary McCloskey, Castle Priory College, Thames Street, Wallingford, Oxford OX10 0HE. Telephone Wallingford 37551.

The Conference takes place very soon, so don't delay if you feel you would like to attend.

TV LINK passes its century

SINCE IT began transmission in January, 1976, LINK has established itself as the only regular television programme for all disabled people. And in November, it celebrated its centenary edition with a special Remembrance Day film about disabled servicemen.

Over the years, LINK has catered for people with every form of disability—physically and mentally handicapped, blind and deaf—and also for their families, friends and helpers. Essentially a magazine programme, it has provided valuable information with regard to benefits, aids and services as well as dealing with the major issues of the day which affect disabled people.

Produced by Central Television, one of its most popular features is the demonstration of various types of living aids by Niam McAleer.

And among the most noteworthy of earlier programmes was a profile of the conductor Jeffrey Tate, who has spina bifida.

Rosalie Wilkins has presented LINK from the very start.

Recently, she has been joined as presenter by 32-year-old former freelance journalist Kevin Mulhern.

LINK, produced by Central Television, is transmitted every other Sunday morning. The time may vary from region to region, so check your local press or TV Times.

THE FOLLOWING benefits were increased as from November 22. If you would like further details, ask for leaflet NI1 196 from DHSS local offices.

Unemployment Benefit: The standard rate of unemployment and sickness benefit went up from £22.50 to £25.00 for a single person, and from £36.40 to £40.45 for a married couple.

Child Benefit: Increased by 60p to £5.85 a week for each child. One-parent Benefit increased from £3.30 to £3.65 a week.

Family Income Supplement: The maximum level of income which will still entitle you to FIS went up from £74.00 to £82.50 a week for one child families, and the additional amount for each further child increased to £9 a week.

Mobility Allowance: Increased from £16.50 to £18.30 a week, and the allowance is no longer liable to tax.

Increases in Benefits

Attendance allowance, non-contributory invalidity pension: Increased by 11 per cent.

Earnings rule: The amount which can be earned by someone looking after severely disabled people at home, without affecting their right to *Invalid Care Allowance*, went up from £6 to £12 a week. The Allowance itself went up to £19.70 per week (from £17.75).

The amount of net earnings from work of a 'therapeutic nature' which can be received without loss of benefit by claimants to sickness, injury or invalidity benefits increased from £16.50 to £20.00 a week.

Supplementary Benefit: A single householder's ordinary scale rate went up from £23.25 to £25.70, and a couple's from

£37.75 to £41.70. The long-term householder rate went up from £29.60 to £32.70; for a couple from £47.35 to £52.30. The limit on the amount of capital a person can hold and still receive supplementary benefit went up from £2,000 to £2,500, restoring its 1980 real value. Supplementary benefit *heating additions* for those with extra heating needs increased by 15% in line with the estimated rise in fuel prices. The basic rate heating addition went up from £1.65 a week to £1.90, and the higher rate heating addition from £4.05 to £4.65 a week.

Make a New Year's Resolution to check that you are receiving all the benefits to which you are entitled! Ask at your local DHSS office, or contact your Local Association Secretary or ASBAH Field Worker.

Importance of Independence

THE ROYAL Association for Disability and Rehabilitation (RADAR) is holding a one-day seminar on *Self-Care Training for Physically Handicapped Children* on February 24 this year. The speakers, who include Barbara Newman of ASBAH, representatives from further education and the careers service, will talk about the difficulties faced by handicapped children if they are not independent, and how they can be helped towards independence.

Details from the Conference Officer on 01-637 5400.

Learning, Loving and Living

IN THE summer ASBAH will be contributing to the Second International Conference organised by The Association to Aid the Sexual and Personal Relationships of the Disabled (SPOD). Entitled *Learning, Loving and Living* it will be held at Owens Park, University of Manchester from July 19-22.

More details from the organiser, Christine Taylor, 33 Grantham Road, London W4 2RT.

Jobs—it's important to stay in touch

UNEMPLOYED people over 18 are no longer required to register for work as a condition for receiving Unemployment and Supplementary Benefit. This new law came into effect in October.

But the Manpower Services Commission points out that Jobcentres and Careers Offices will continue to offer one of the best ways of finding a job and most people will benefit by continuing to use them to look for work.

This is particularly true for disabled people.

'In the first place there is the Disablement Resettlement Officer (DRO) who is specially trained to recognise and help overcome your employment problems, and to talk to employers about them. He is also the link to the wide range of specialist services provided by the MSC to help you find or keep employment,' says the MSC. These specialist services include training courses at Skillcentres, and Colleges of Further Education, with employers, or at one of the four residential colleges specialising in the training of severely disabled people for open employment. There are work preparation courses, too.

Grants are available to certain registered severely disabled people whose disability means that they cannot use public transport to get to work, and therefore, have higher travelling costs.

The MSC can arrange the free loan of special tools or equipment to help a disabled person.

Grants may be paid to employers who need to adapt their premises or equipment to enable them to recruit a disabled person.

The Jobcentre can also help find work if necessary in a sheltered workshop or sheltered industrial group in open industry.

Registration in the Disabled Persons Register is entirely voluntary, but may make it easier to find a job. The MSC points out the two main advantages—'That employers with over 19 employees have a duty to employ a percentage of registered disabled people, and certain facilities are available only to those who have registered as disabled'.

The MSC leaflet *Into Work* is a brief guide to its services for disabled people. Copies are available locally at Jobcentres and Careers Offices and from DRO's.

It is the quality of life that is important

I HAVE READ with interest the letters written by Alison Davis and Diana Sanderson. I also have spina bifida, am married (my husband had polio as a child and is confined to a wheelchair too), and have a six year old daughter.

The one way in which I differ from the others is that I did not go to University, perhaps this lack is the reason for me being able to see the other side of the situation.

I do not, for one moment, think that the doctors are suggesting that any of us should be 'killed off', rather, they are admitting to mistakes made in the past—namely keeping alive at all costs children who are now condemned to an existence. Surely it is the quality of life that is important, and not its length.

We have been lucky and have been able to live near normal lives, many never will. I admit that Professor Lorber's description of us is not exactly flattering, but in some cases it is probably correct.

When I was expecting my baby, I had amniocentesis. If the test had proved that the unborn child had spina bifida (or any other disability), I would have had an abortion without hesitation—not because it would be difficult for us to have coped with a disabled child, but simply because I would not knowingly bring a disabled child into this world.

By all means let us show everyone how well it is possible to overcome our disabilities, but let us also be realistic.

Mrs Susan Seager
Pickering, Yorks

Prof Lorber replies to his critic

AS MRS SANDERSON mentions my name in her letter in the September/October issue, I think I must reply that she misunderstands the policy and practice of dealing with spina bifida babies.

Nobody is being killed and no doctor would ever consider not treating the type of person that Mrs Sanderson is. Anyone with experience with such babies and children knows very well that what many of them can and have achieved. They can also tell with very great precision just which of them can achieve as much as has Mrs Sanderson, as well as others who may achieve less but still have worthwhile lives.

It is the profoundly handicapped, who are getting fewer and fewer, who pose the question whether active treatment is of benefit or not, and it is here that very full discussion, based on accurate assessment of the individual baby, is so necessary with the parents. There is no great rush to do this and there is no need to pressurise parents into active treatment or to make a final decision against it.

I have not described people like Mrs Sanderson as 'clumsy, fat dwarfs', although unfortunately there are some very severely handicapped young people who are fat and are very small.

Prof. John Lorber MD (Cantab), FRCP.,
Sheffield

Disabled Living News

A small and inexpensive little item has proved a great boon at ASBAH's independence training programmes for young people . . . it's a pocket bath

thermometer, which floats in the bath and lights up to show if the water is 'too cold', 'just right', or 'too hot'. Making sure that the bath is not too hot before you get in can be a great problem if you are paralysed from the waist down. This thermometer solves it for you. Try to get one at a good local chemist or direct from: Rolenworth Ltd., 1/3 Grey's Road, Henley on Thames.

* * * * *

As many readers will probably remember, ASBAH and other voluntary organisations were involved in advising on the design

IT WAS A SAD END to the year because we said goodbye to Senior Disabled Living Adviser, Jill Vernon, who has played such a vital role in ASBAH's work over the past six years.

Her work to launch ASBAH's much praised and valuable independence training programme has been of special importance, and young members and parents all over the country will have benefited from her advice and personal interest.

She left to become Deputy of the hostel at the Kerensa Centre in St Austell, Cornwall. This is a short-term assessment and rehabilitation centre for physically handicapped adults.

of a Handicapped Child Seat for the car, manufactured by Britax. Those of you at this year's Naidex will have seen that Britax has now brought out a **carrier** for this seat.

It is an American idea—a lightweight folding frame which means that the child can be lifted in the seat from the car and straight onto the carrier which then becomes a kind of lightweight buggy. It is not suitable for long distances but might fulfill a need when it comes to having to make several short trips and changeovers from car to pushchair.

More details from Britax-Excelsior Ltd., Chertsey Road,

Byfleet, Surrey KT14 7AW.

* * * * *
Another new aid to mobility that was on show at Naidex is the Streamliner, a very **slim folding wheelchair**, the wheels of which can be quickly removed to convert it into a pushchair, if necessary. It would be very useful for holidays, and might be the kind of item that a local association could purchase for use by its members for special journeys etc.

More details from The Spastics Society, Unit 4, Dolphin Industrial Estate, Southampton Road, Salisbury, Wilts. Tel: Salisbury 20441.



I have heard that if you take vitamins during pregnancy it can help to prevent your baby having spina bifida. One of my

brothers had it and my own son, Philip, was born with spina bifida and hydrocephalus. My daughter recently got married and wants to start a family and I wonder whether there is a risk of her children being affected. Is there anywhere she can get advice?



When there have been spina bifida children in a family the chances of it happening again are greater and you are right to be concerned. Your daughter and her husband should ask their GP

to refer them to a genetic counsellor who could advise them on the degree of risk and make sure they are given proper advice about tests during pregnancy.

Research seems to show that, if a woman at risk takes vitamins *before* she conceives and during the early part of pregnancy, spina bifida can be prevented: a trial will be done this year to find out for sure. Meantime, since these vitamins cannot be bought over the counter, your daughter should discuss this with her own doctor.

Rosie Horsfall, Disabled Living Adviser



We have a 9 year old daughter with spina bifida and hydrocephalus and would like to take her to the USA next year to visit

Disneyland. Is it possible to get insurance cover for her in case she needs emergency treatment whilst we are there?



Several companies provide holiday insurance cover for disabled people with a pre-determined condition. I would suggest that you go along to your local ABTA Travel Agent and ask them to arrange the 'Extra Sure' travel policy. This gives

cover of £100,000 for visitors to North America and £50,000 for the rest of the world.

As a further precaution when travelling abroad it is always useful to know the address of the Spina Bifida Association in that country. ASBAH's Information Officer has a list of these.



We are thinking of emigrating to New Zealand and would like the address of the New Zealand Association to find out

what facilities are available regarding education and medical treatment for children with spina bifida.



Before you go any further with your application may I suggest that you contact New Zealand House, Haymarket, London SW1 to see what their rules are regarding immigration. Some countries have a strict policy that people with a

congenital disability such as spina bifida are not allowed to enter the country with a view to living there permanently. Please do check before you go any further with your plans that you fulfil the criteria for emigration to New Zealand.

In the meantime, the address of the New Zealand Association is: Mrs D Reynolds, New Zealand Crippled Children's Society, 148 Rutherford Street, Nelson, New Zealand.



I took my 6 month old baby to the doctors recently to have her vaccinated against whooping cough. My doctor said he did not

think this advisable because she has hydrocephalus. Is this right?



If a child with hydrocephalus has been fitted with a shunt to control the hydrocephalus many paediatricians feel that there could be problems for the child if he or she is vaccinated against whooping cough. However, the diphtheria, polio,

tetanus, measles and chicken pox vaccinations should not have any ill effects.

Beverley Holland, Information Officer

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

● straightforward fitting and removal.

● secure adhesion that allows the skin to breathe

● protection for the wearer and for the seal from urine flow-back

● clean and simple emptying

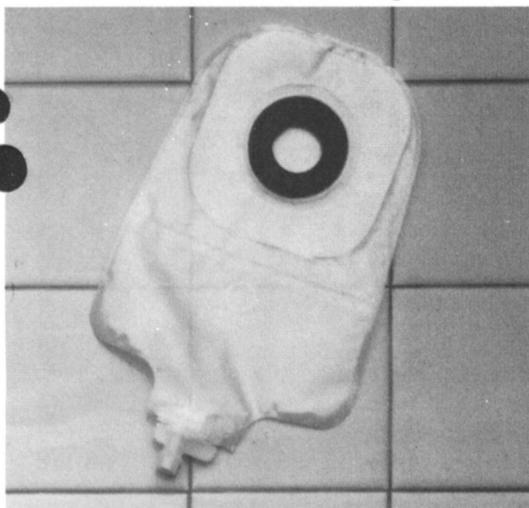
● outstanding protection against leakage

● virtual elimination of peristomal wafers

● easy night drainage

Lo-Profile* urostomy bag by Hollister

Probably the most advanced urostomy bag in the world.



The Lo-Profile* urostomy bag by Hollister certainly lives up to its name. Its special design and shape ensures that it passes unnoticed under clothing. You can be sure, however, that its other benefits will not pass unnoticed.

Take for example the drainage tap. It's so much more convenient and hygienic than the plugs or bungs found on some other appliances.

Then there is the protection against leakage with the Karaya 5* seal and the secure adhesion of the new Microporous II

square, not to mention the new easy-to-fit night drainage tube.

In fact the more you see of the Lo-Profile* urostomy bag by Hollister, the more you may come to think it deserves a high profile.

Request to try the Lo-Profile* urostomy bag by Hollister

Please send me a supply of Lo-Profile* urostomy bags by Hollister:

Name: _____

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Actual Stoma Size: _____

Type of bag required:

Series 143-Lo-Profile* urostomy bag by Hollister with Karaya 5* seal and Microporous II adhesive

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Please tick relevant box and post this coupon to Abbott Laboratories Ltd., FREEPOST, Patient Care Division, Queenborough, Kent ME11 5BR.

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THERE are three main ways of arranging a holiday abroad.

1) Arranging it yourself: This involves writing or telephoning hotels and travel companies to arrange accommodation and travel. This is not the easiest way, but it does allow you to be more independent and flexible.

2) Making arrangements through a travel agent: His job is to find holidays for people and to book transportation and accommodation to suit individual needs. It is advisable to make sure he is a member of ABTA (The Association of British Travel Agents).

3) Book a Package Tour: This is generally the easiest and cheapest method. Details of these holidays may be found in tour operators brochures obtainable from your travel agent, and the booking is usually made through him, although some tour operators prefer you to book with them direct. Not all accommodation offered will be suitable for disabled people so you should explain your special requirements to the travel agent.

Some tour operators are now beginning to indicate in their brochures holidays especially suited to people with a disability.

Below are some notes for guidance when arranging your holiday.

- Decide the time of year you wish to travel. Excessive heat can often cause problems, and spoil your holiday. An advantage of an off-peak holiday is that it is usually cheaper than July or August, which are the hottest and most crowded times.

- Unless you can manage without any help whatsoever, do not plan on travelling alone. It is unfair to rely on hotel staff or resort representatives or to take advantage of the good-will of other holidaymakers if you need help either to get around or with your personal care.

- Plan well in advance and book early.

- Find out as much as you can about the area you wish to visit so that you will be able to take advantage of the facilities and places of interest.

- Be completely honest with your travel agent about your

FOR MANY people with a disability the prospect of a holiday outside this country has until recently been only a dream. Now more and more travel companies and travel agents are becoming aware of the vast untapped market of people with special needs who would like to get away for a few days in the sun.

Travelling Abroad!



A PHAB holiday on Italy's Lake Garda

requirements and any particular problems you may have. Some hotels are not keen to take incontinent people whilst others will be very happy to accommodate you in any way they can providing they know what is needed.

- It is essential to make sure you have adequate insurance cover, please do check your insurance policy carefully to make sure your needs are covered. Your ABTA Travel Agent will be able to arrange for the 'Extra Sure' travel policy which gives cover of £100,000 for visitors to North America and £50,000 for the rest of the world. With this policy there are no restrictions on cover for a predetermined condition. Many other insurance companies provide holiday insurance for disabled people provided certain conditions are met.

- If you are travelling by air the airline concerned may insist that you have a medical certificate of fitness for air travel. Ask your travel agent or tour operator if this

is required and if it is get one from your doctor.

- Make sure that you take an adequate supply of medicines and any dressings or extra equipment you may need, it may be very expensive or even impossible to buy them at your destination.

- For travellers to countries in the EEC and also some other countries the UK has a reciprocal health agreement. Full details of how to obtain medical treatment through the national health services of EEC countries are contained in leaflets SA/30 and SA/36 obtainable from your local DHSS office. With leaflet SA/30 is an application form which has to be completed and returned to the DHSS. If you qualify you will be issued with a certificate of 'entitlement to treatment' (form E111) which is recognised throughout the EEC. Details of reciprocal health care agreements with other countries outside the EEC are also contained in leaflet SA/30 from your local DHSS office.

There follows a list of tour operators willing to advise disabled people on holidays. Details unless otherwise stated may be obtained through your travel agent.

British Airways (Enterprise Holidays & Sovereign Holidays)
Co-Op Travel
Horizon Holidays
Kuoni Travel
Meon Villa Holidays
P & O Air Holidays
Pontinental
Saga Senior Citizen Holidays

Spes Travel
Swans Holidays
Thomas Cook Holidays
Thomson Travel
Tjaeborg Ltd

Other travel companies specialising in holidays for disabled people.

Threshold Travel
Wrendal House, 2 Whitchurch Street West, Manchester
Chalfont Line
4 Medway Parade, Western Avenue, Perivale, Greenford,

Essex
Fourwinds Holidays
PO Box 20, 42 Devonshire Street, London W1
Travel Well
8 Southampton Row, London W1
Winged Fellowship Trust
2nd Floor, 64/66 Oxford Street, London W1

All that remains is to say pack plenty of suntan lotion and have a good time!

BEVERLEY HOLLAND
Information officer

Continued from Page 3

lawful positive discrimination. But can we in practice properly distinguish between positive and negative discrimination? My contention is that we cannot. We cannot call to aid the analogy of women and black people, where equal opportunity legislation relies on the principle of equal treatment. For disabled people, the aim cannot be equal treatment. The cause of genuine complaint among disabled people is that historically they always have been treated as equal, and in a world which necessarily is geared primarily to suit able-bodied people, they have invariably lost out.

From the United States, alongside the anti-discrimination movement, comes the 'rights' movement. The concept of rights is inherent in the United States constitution, whereas in Britain it is not. But the idea has percolated across, and the message is

that disabled people must act aggressively on their own behalf, and interfering able-bodied people must keep out.

An axiom of the rights movement is that it is only disabled people who know what it is like to be disabled, and only disabled people are therefore entitled to speak on behalf of the disabled. The proposition is transparently untenable; do we similarly say that only the unemployed should speak on behalf of the unemployed, or that women novelists should not write books about the affairs of men?

Among those of us who are disabled, our views of disability problems are invariably affected by our own specific and personally unique experiences, and perhaps we should sometimes ask ourselves whether we are better equipped than people who are not disability-involved to speak impartially on behalf of 'the disabled'.

INCO[®]CARE Insert Pad and Ventilated Pants

The new Inco-Care Insert Pad is highly absorbent yet still discreet enough to fit securely and comfortably into the Inco-Care Ventilated Pants. It's new quilted lining disperses urine to reduce soreness, irritation and odour, with fluffier filling to absorb the average bladder release with capacity to spare.

The Insert Pad has a special waterproof backing, with no plastic-to-skin contact to help prevent leakage without causing discomfort... And teamed with Inco-Care washable, stretch Ventilated Pants, the two together create an incontinence system that looks like and feels like normal underwear, restoring patient dignity and providing more comfort, confidence and convenience.

Inco is a registered trade mark.

Wheat Bridge, Chesterfield, Derbyshire, S40 2AD.
Telephone Chesterfield (0246) 31101. Telex 547320.



'For continence?'

'Yes, looks and feels like normal underwear.'

Write or telephone for samples and further details.

Robinsons of Chesterfield



Book Shelf

THREE new titles have emerged recently in the excellent Human Horizon Series from Souvenir Press. All three are informative, interesting and easy-to-read, which is probably due to the fact that all three are based on personal experience, and a wish to communicate.

No Handicap to Dance

by Gina Leveté

THIS BOOK tells how dance teachers can use improvisation, mime and dance with handicapped people. In a climate where it is much more generally accepted that creative expression can enrich the lives of disabled people, it is to be hoped that this publication will be widely used.

Much of the favourable climate is due to Gina Leveté herself. She describes in *No Handicap* . . . how it all started and how she eventually managed to persuade a special school to let her hold dance lessons for the disabled pupils. The success with this group led to an invitation to carry on the dance movement at Queen Mary's Hospital, Roehampton in a unit which had a special interest in thalidomide and spina bifida children.

'The spina bifida children were far more timid (than the thalidomide children). They needed a lot of encouragement to get out of their Chailey Chariots which are like go-carts. Once out, they shunted around on their bottoms or stomachs with joy', writes Gina Leveté.

'When very young, they have difficulty in recognising the feel of different surfaces. So again tactile movements were introduced. "Can you put your forehead against a surface that is cold?" I would ask. "Put your back against something soft. Touch everyone in the room who has curly hair", and so forth. Great care was needed to ensure that their brittle little bones did not fracture because, due to their paralysis, they would not feel the break.

'Despite this, they quickly grew to be adventurous, discovering

different movement combinations for travelling across the room. All the children under the age of 12-14 preferred to be without artificial limbs or calipers. Everyone from parents to staff agreed that the classes were successful in "thawing out" these small people who came into hospital'.

The book includes the story of how Gina Leveté started the development of Shape which is now a wide ranging organisation of artists performing and developing creative activities for the disabled and disadvantaged—in hospitals, centres for the homeless, youth groups, day centres, prisons, and so on.

Much of the book is devoted to a practical guide to creative movement sessions with many ideas for practical exercises, improvisation, relaxation, mime and stories for different age groups and different handicaps.

It ends with a list of useful addresses and further reading.

Price: paperback £4.95, casebound £6.95.

Gardening is for Everyone

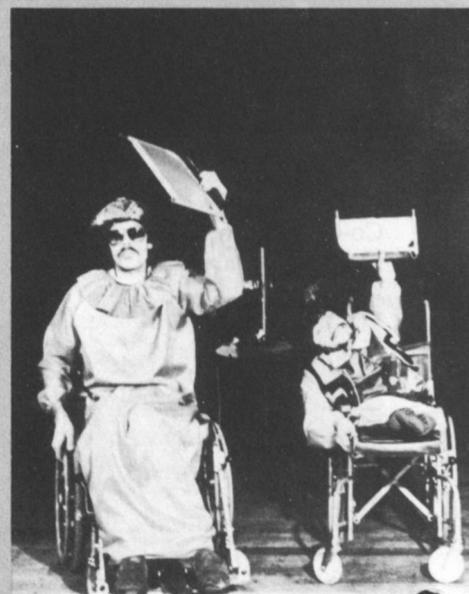
by Audrey Cloet and Chris Underhill

THIS VERY practical 'gardening diary' will give pleasure and ideas to any would-be-gardener, disabled or not. The advice is simple to follow, and the equipment described can all be obtained 'at your local shop'—one of the points that Audrey Cloet insisted upon.

The book starts with basic advice on garden planning, shelter, tools and tool adaptations, seed sowing, potting composts, fertilisers and drainage.

The main section is a week-by-week guide to gardening activities to take you right through the year. It gives suggestions for easy and rewarding tasks that are not too time-consuming.

It is not all straightforward gardening, but includes details of flower pressing and bulb planting, of how to make Christmas decorations, and how to create a dish garden and a miniature garden.



Members of the Graeae Company in The Miss Crippled Universe Sponsor. Photo: Bob Chase, from 'Disability, Theatre & Education'.



Gina Leveté, the author of *No Handicap to Dance* giving a dance session to disabled children during the early days of her work.

Audrey Cloet is editor of *Growth Point*, the magazine of the Society for Horticultural Therapy and Rural Training, and Chris Underhill is founder and Director of the Society.

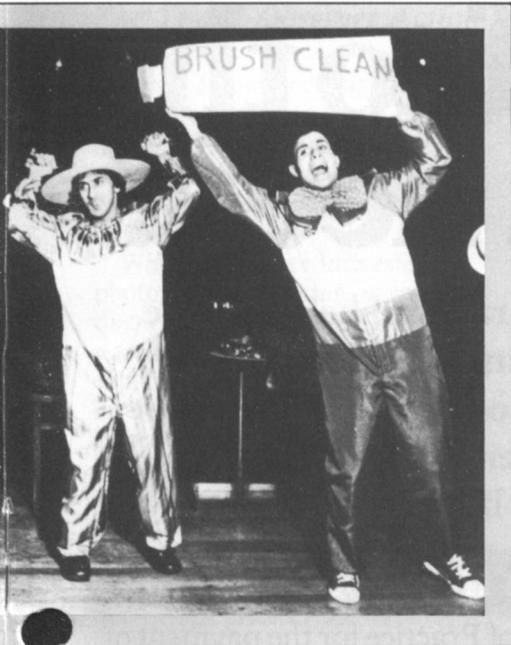
Price: paperback £4.95, casebound £6.95.

Disability, Theatre and Education

by Richard Tomlinson

THE AUTHOR, who is Headmaster of the Thomas Delarue special school at

Book Shelf



Tonbridge in Kent, looks at the growth of theatre by disabled people, and in particular the emergence of the Graeae Theatre Company, a touring group of disabled professional actors and actresses. He also discusses the work of other groups of disabled actors throughout the country.

The book explores some of the methods used by Graeae to explore issues in schools, and methods by which disabled people can be actively involved in workshop sessions. Graeae's workshop methods when working with the disabled and able-bodied are looked at in some detail, and there is a Chapter which goes through the various steps leading to a finished Graeae production. Another chapter is devoted to a full script, *M3 Junction 4*, written by the author for the Graeae company.

The book will prove useful to anyone interested in setting up a group.

Price: paperback £4.95, casebound £7.95.

Sexuality and the Physically Disabled—an Introduction for Counsellors.

THE AIM of this book is to give counsellors information about various disabilities and outline possible implications for sexual and personal relationships.

The introduction says: 'Some aspects of growing up, such as

menstruation and masturbation can be made more difficult by physical disabilities. In the formation of intimate relationships, there may be extra problems to cope with, such as incontinence, impotence and negative self-image.

Subjects such as contraception, parenting, positions for sexual intercourse, homosexuality, effects of drugs, may also require special consideration'.

The book arose out of the work of the IYDP Committee and Beverley Holland, ASBAH's Information Officer was one of the compilers.

Available from SPOD (The Association to aid the Sexual & Personal Relationships of the Disabled), The Diorama, 14 Peto Place, London NW1 4DT. Tel: 01-486 9823. Price £1.70 to include postage.

Playaids for the Handicapped Child

THIS is a useful, well-illustrated catalogue showing a wide range of toys and play equipment, with information about therapeutic value, and suggestions for how best to use them.

The items are grouped under the names of the different manufacturers and suppliers which include research units, individuals, workshops and organisations like Active.

The catalogue follows on from the successful exhibition, 'Playthings for the Handicapped Child'.

The catalogue, price £1.50 including postage is available from The Handicapped Persons Research Unit, Newcastle Upon Tyne Polytechnic, No 1 Coach Lane, Coach Lane Campus, Newcastle Upon Tyne NE7 7TW.

Ask The Children—Experiences of Physically Handicapped Children in the School Years

by Nicola Madge & Meg Fassan
CHILDREN aged between 7 and 16 from special and ordinary

schools in London were questioned about their understanding of their own and others disability. They were then asked to talk about their lives, their friendships, their families and the future.

The result is a sensitive study which fills a number of gaps left by existing literature, and makes a valuable contribution to the current debate on the merits of integrated versus segregated education for handicapped children.

Published by Batsford Academic at £5.95.

Disability In Adolescence

by Elizabeth M Anderson and Lynda Clarke with Bernie Spain
THE LATE Elizabeth Anderson's book, 'The Child With Spina Bifida' which she wrote with Bernie Spain, has always been regarded as an authoritative work on the problems and difficulties of children with spina bifida and hydrocephalus.

This latest work, published posthumously looks at the social and psychological needs of disabled adolescents. Two groups of disabled teenagers, one with cerebral palsy, the other with spina bifida and hydrocephalus, took part in the study.

The findings underline the need for a counselling service while the teenagers are still at school, and the need to rationalize the piecemeal and overlapping provision of help for disabled school-leavers.

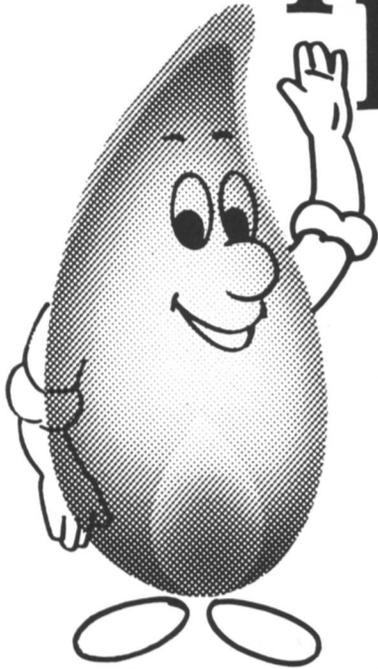
This book provides a wealth of information of direct use to those concerned with disabled teenagers and their families, whether in careers advice, work placements and alternatives, further education, counselling and medical services.

It is unfortunate perhaps that the list of useful addresses given at the back of the book contains a great deal of out of date information.

Published by Methuen & Co. Ltd, price on application.

Continued on p.15

“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, 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

The Young Observer Action Guide

by Betty James and Pat Salmon
THIS USEFUL book will help you to find out about the activities you've always wanted to try, or which have suddenly caught your imagination.

Whether you are interested in photography, cooking, custard-pie throwing, goat herding, bird watching or lace making, the guide explains how you can follow your interest near your home or holiday resort.

Included is a special section on activities for disabled people, but many of the other activities listed would be equally suitable.

Available from all good bookshops price £1.95.

Parents and The Handicapped Child—A Guide for Families

by Margaret R Marshall
DISCOVERING that your child is handicapped is a shock for all parents. Margaret Marshall's expert advice is given in a straightforward but sympathetic way, dealing with the practical and emotional problems for all those involved.

As Ms Marshall says: 'This book is intended to indicate some of the ways in which shock can be survived and channelled into aiding all those in the home of the young handicapped child'.

It succeeds very well outlining organisations which can offer help and support as well as suggesting books and toys for the child.

Published by Julia MacRae Books price £6.95.

Footwear & Footcare for Disabled Children

by Janet Hughes, MCSP
THE DISABLED Living Foundation have long been concerned about the footwear problems of people with a disability. This easily read and very useful guide is the result of that concern.

Designed for parents, professionals and non-professionals it is simply written and clearly illustrated. Everyone concerned with the care of

Continued from p.13

Book Shelf

children's feet whether they are disabled or not will find the information on foot abnormalities and problems, their treatment and general care, very helpful.

The book is available from DLF (Sales) Ltd, 43 East Hill, Wandsworth, London SW18 2QZ, price £5.25 including postage and packing.

*** Janet Hughes is going to write a special article in the next LINK on footcare problems of those with spina bifida.**

In Brief . . .

Fundraising A-Z by Alun Robinson. Ideas for money-raising which local associations might find useful. Price £1 including postage from: Kirkfield Publications, 56 Henley Avenue, Dewsbury, West Yorkshire.

Patients' Rights: This publication tells you all about your rights under the National Health Service. Price £1.50 from your local

Community Health Council. There is also a summary which is free. *Guide des Autoroutes at L'usage des Personnes a Mobilite Reduite* is a guide to services for the disabled on motorways in France. It is free from: Ministere des Transports, Direction des Routes, Service du Controle des Autoroutes, BP 70, F69672 Bron Cedex, France. It is written only in French but the system of symbols used is also explained in English, and German.

The National Bureau for Handicapped Students has the following useful leaflets. Available from NBHS, 40 Brunswick Square, London WC1N 1AZ. Tel: 01-278 3459. Prices include postage. Please send money with order: Financial Assistance for Students with Disabilities 1982/3 40p
Information Sheet No 1: Applying to University or Polytechnic, Some Notes for Disabled Students, Parents & Advisers 20p
Information Sheet No 2: Meeting the Personal Care Needs of Severely Handicapped Students at College 20p
An Educational Policy for Handicapped People 15p
Further Education, Training & Employment Opportunities for Handicapped People £1.50



Mark Sellwood, 15, of the North Yorkshire Association with members of the Derwent Venture Scouts of York, beside the raised garden which they were building for Mark in the garden of his home. Mark greatly enjoys gardening. He has grown salad vegetables and seems to have green fingers when it comes to courgettes. Mark and his family have been members of the North Yorkshire Association for 14 years. The Derwent Venture Scouts have proved themselves good friends of the Association in many ways—not least by running a camp which Mark and his spina bifida friends have attended.

Number work and mathematics

Study looks at the abilities of spina bifida children.

SINCE the occurrence of spina bifida children in schools is a relatively recent phenomenon, teachers, parents and others interested in their welfare, are as yet uncertain about their true educational potential.

Indeed, one has sympathy with the concern expressed by ASBAH (1975) when it asked "Are spina bifida children intellectually impaired and, if so, in what ways? What effects are these children's special learning difficulties likely to have along with their physical problems in classroom performance? What can teachers do to help?"

There are many such children who need special educational provision. This is true at each stage as they progress through schools, and later on into further/higher education.

It is understandable in the light of the children's physical handicap which are frequently severe, that those who work with them express concern as to their intellectual abilities. Indeed, it might be all too readily assumed that the effects of hydrocephalus, paraplegia, sensory loss, incontinence, and deprivation of natural early learning experiences would combine to cause irreparable retardation. It is easy, therefore, to see how very unfortunate it would be, if as well as their physical disability, these children had the added problem of labels attached to them such as 'Many are going to be mentally retarded'. 'Within the spectrum of disability the majority will have mental handicaps'. 'Most cases are sufficiently handicapped both physically and mentally'.

Such statements directed at the whole spina bifida population are as unhelpful as they are unsound; unhelpful because a premature and subjective impression that spina bifida children are by definition also mentally retarded influences educational programmes, expectancy, and placement; unsound because, in itself, the term 'spina bifida' covers a very wide range of physical abnormality and it is inevitable that there will be a wide range of intellectual ability.

Clearly there will be spina bifida children, particularly those with the more severe form, myelomeningocele and possibly having a shunt to alleviate hydrocephalus, whose specific learning may be worsened by various factors. Such children may be slower than usual in development of basic visual skills, such as the ability to recognise and reproduce shapes, and of basic spatial skills such as the ability to judge distances. Also frequent and lengthy periods spent in hospital may adversely affect their educational progress.

One area of particular concern is mathematics where the consensus of teachers and researchers is that spina bifida children in general find particular problems.

It is understandable if teachers assume that, for various reasons, spina bifida children have 'a blind spot' for mathematics in much the same way as some children with reading problems are thought of as

dyslexic. However, this type of assumption is dangerous. In the first instance, if a group of children is designated as having no potential in a given area, the curriculum will be constructed with this in mind, and time given on the timetable will be minimal. This will mean that only limited goals will be attained. Although on face value this approach is commendable there is, nevertheless, a danger that a curriculum based on limited goals can inhibit achievement and the child's true potential remain unrealised.

The teacher is faced with a dilemma; if, as is commonly thought, spina bifida children have a definite recognisable inability to develop mathematical skills, then a limited and practical curriculum is reasonable. If, on the other hand, the observed weakness is due to other problems, it would seem sensible to explore this with the aim of planning remedial measures and curricula relevant to a wide range of academic needs. Some of these 'other problems' are deprivation of early learning experiences, perceptual immaturity (referred to earlier), not enough teaching, low expectancy from all concerned and the general educational malaise which is frequently associated with handicap.

As a first step in an investigation it was decided to study the acquisition of certain fundamental number concepts by some of the more handicapped spina bifida children, and to compare this with that of their non-handicapped peers.

If it could be shown that spina bifida children appear to pass through normal stages in the development of number concepts and become competent despite being held back by the complex nature of their disabilities, it seems reasonable to suppose that given a stimulating, expectant environment and understanding teachers they ought to be able to move naturally on from a level of thinking which is assisted by practical situations to a level which is independent of these.

A group of 130 spina bifida children were tested, 90 of them with shunts. These children attended special schools in Derbyshire, Leicestershire and Nottinghamshire. These tests were based upon the work of Jean Piaget whose ideas have greatly influenced mathematical education. Other areas of development such as language, hand-eye coordination and reading skills, all of which can affect competence in mathematics, were considered.

The following questions were asked:

1. Do children with different degrees of spina bifida and hydrocephalus pass through normal stages in the development of number concepts?
2. Is there a significant difference between the development in children with and without a shunt?
3. Is there a significant correlation between number

skills and the degree of handicap?

4. Is there a significant difference between spina bifida boys and girls?

5. Do spina bifida children have specific perceptual problems which may influence their number and mathematical development?

6. Do spina bifida children continue to acquire vocabulary skills, as they evidently do at the pre-school age?

7. Is the level of reading attainment below average at each age?

Conservation of quantity: If 10 counters are placed in a row and then are moved close together, are there still as many?

One-to-one correspondence: Given a number of egg cups, place an egg by each. Or, given 10 marbles in a line, make another matching line.

Seriation: Place ten rods of differing lengths in order of increasing size.

Class inclusion: Given a set of wooden beads most of which are brown and two of which are white, then are there more brown beads or more white beads?

The 130 spina bifida children tested (64 boys, 66 girls) had IQs ranging from 49 to 130 with an overall mean IQ of 80.9. Their ages ranged from 5-16 years (mean age 9.5 years), and they were born between 1959 and 1971. It was observed that overall those with a shunt had considerably lower IQs (77.7 compared with 88.1). The mean ages of both groups were the same (9.5 years). The sample was also classified according to the degree of physical disability—minimal, moderate, severe, very severe.

Research findings.

Analysis of the results indicated that spina bifida children *do* pass through the same stages in the acquisition of number concepts as do the non-handicapped, and also respond in similar fashion to Piagetian test situations.

The important difference, however, was that whereas the non-handicapped child attains competence during the early years of the junior school, the children in this sample were reaching comparable conceptual levels as they approached secondary age. Most of the infants up to the age of seven had not developed the mathematical concepts tested. Those of junior school-age showed an increasing grasp of these concepts, albeit with some fluctuations. With very few exceptions, the secondary age children had fully grasped these fundamental concepts.

Children without shunts did better on the Piagetian number tests than those with shunts, but the difference was not sufficient to be classed as 'statistically significant'. When, however, responses to specific concepts were analysed, it was found that children without shunts were significantly more successful when it came to seriation (explained earlier), ordination and cardination, and relations between parts and wholes.

The data indicated that in the Piagetian number tests those with severe handicap were retarded a little more than those with slight handicap.

Although the boys were consistently more successful

the difference in their scores between those of the girls was not statistically significant.

The study supported the view that spina bifida children are likely to have problems of a perceptual nature which could affect their mathematical development. Their performances in the Raven's Coloured Progressive Matrices Test and the Bender Gestalt Test of Visual Perception, reflected considerable perceptual immaturity with specific emphasis on hand coordination. For instance:

Children with shunts had the greatest perceptual problems.

There was evidence that the good progress in acquiring vocabulary skills by young spina bifida children does not continue to develop at the same rate. There was a marked falling away particularly between the ages of 8 and 14. However, there was an encouraging movement towards normal limits as the children approached school-leaving age.

Although the reading tests reflected some reading retardation throughout the major part of school-life there was, nevertheless, a spurt towards fluency from 13 years onwards. In fact, with very few exceptions the 15 and 16 year olds were able readers. There was no significant difference in reading competence between boys and girls, or between those with and without shunts, or those with slight and severe physical handicaps.

Dr Vernon Parfitt, Ash Field School,

Leicester.

Dr David Green, Loughborough University.

Thanks are due to Prof. A. C. Bajpai, the Director of the Centre for Advancement of Mathematical Education in Technology at Loughborough University, for his advice and encouragement.

The next issue will include an article on Perception and the Spina Bifida child by the same two authors.

JOHN GROOMS HOLIDAYS

All facilities specially adapted for wheelchair users (family friends and escorts welcome)

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Self-Catering Units: Near the sea at Barnstaple, Borth, Poole, New Milton, Looe, and a country site at South Cherney, Gloucs.

Holiday Chalets: Near Skegness (Lincs.) Emergency generator for iron lung users.

London Holiday Flat: London, N4.

Motor Caravan: First season 1981. Can be hired for one or two weeks, and driven anywhere in Gt Britain and also the Continent subject to Insurance conditions. It has tail lift, special wheelchair WC/Shower unit, and other modifications. Black & White TV and Radio.

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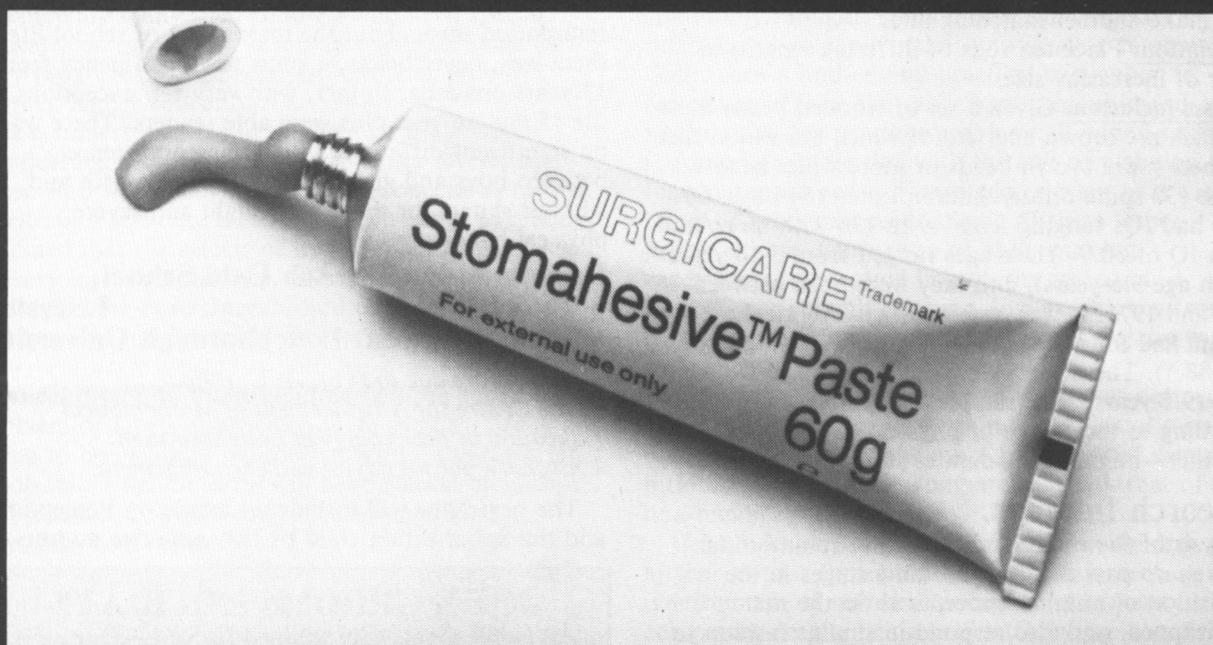
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For further details contact: John Grooms Holiday Department (Ref. L2), John Grooms Association for the Disabled, 10 Gloucester Drive, London N4 2LP. Tel: 01-802 7272.

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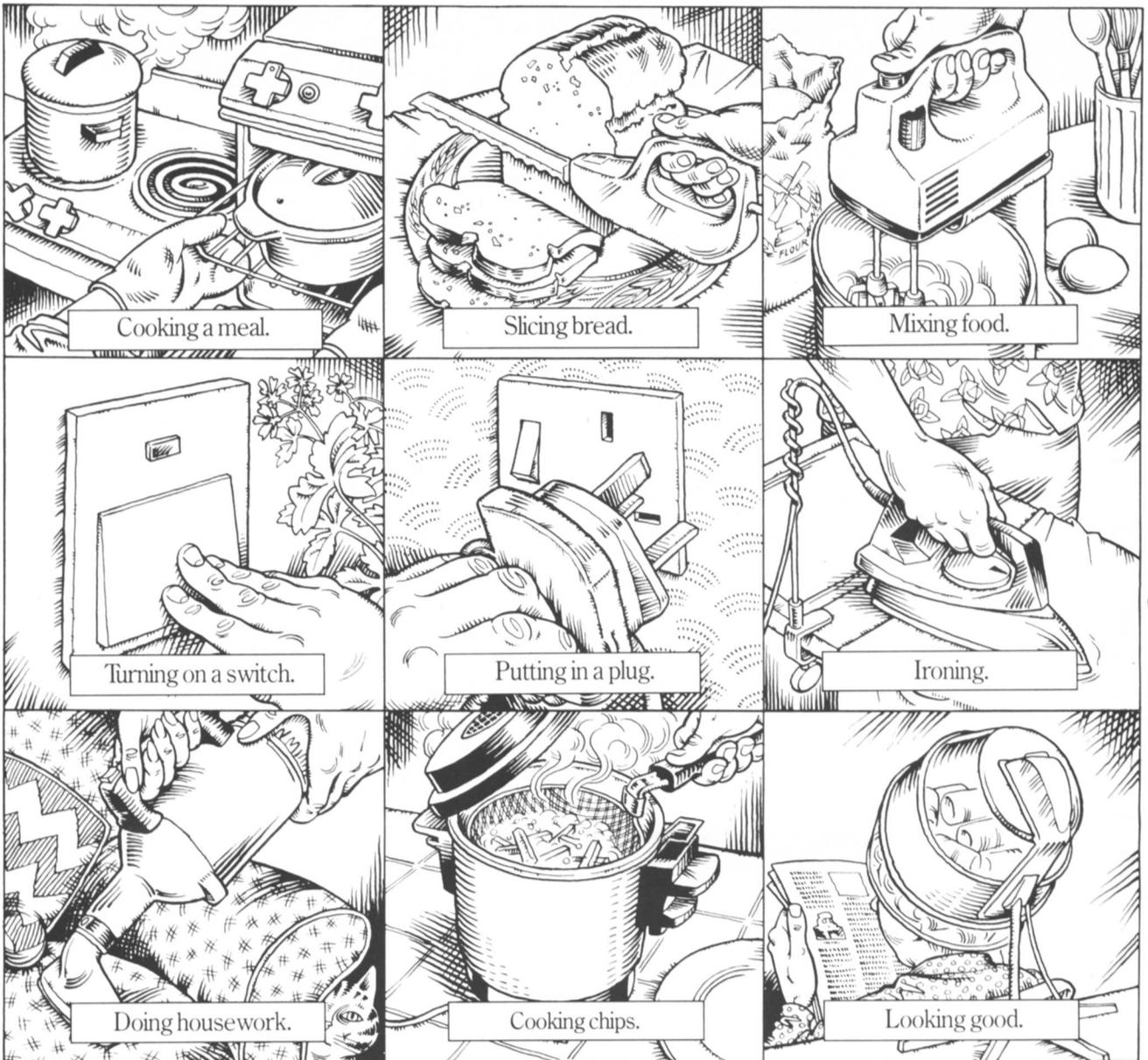
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Below is an Index of some of the major articles which appeared in LINK during 1981 and 1982. Back numbers are available from National Office. It would be much appreciated if you would enclose postage stamps to help us meet the cost of sending these to you.

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Is it this easy in your home?

At your Electricity Board, we have a leaflet called "Making Life Easier for Disabled People".

It contains lots of helpful ideas and lists many electrical appliances which can make life easier.

Appliances such as table-top mini cookers. Electric knives which require only a slight pressure to operate. And small, hand-held vacuum cleaners which can be used for dusting, too.

The leaflet also gives details of brailled controls that can be fitted to

certain electrical appliances. And specially designed attachments for plugs and switches which afford easier handling.

The leaflet is free, from your Electricity Board shop. Or you can write for a copy to the Electricity Council, Information Centre, 30 Millbank, London SW1P 4RD.



THINKELECTRIC
The Electricity Council, England and Wales.

Variety is the spice of fund-raising

In the last edition of LINK, I brought you tidings of three major fundraising events held during September. With so much effort expended and with so much accomplished, most people would be tempted to just sit back and relax. Not so ASBAH's Appeals staff. Before the dust had even a chance to settle they were busy planning new blockbusters.

By the time this latest edition of LINK reaches you, the most dazzling of these events should have taken place. On December 13th, for the second year running, an Auction with a difference is scheduled to take place at Sotheby's. No Ming vases or early Rembrandts will be on offer. Instead, some of the most famous figures from the world of entertainment will be sold to the highest bidder. Among them should be Lulu, Dickie Henderson, Bruce Forsyth, Windsor Davies, Peter (Len Fairclough) Adamson, Paul Daniels, Vince Hill, Ronnie Corbett, Freddie Truman, and Sharon Davies. And for those who prefer our four-legged friends, Red Rum the Superhorse is also likely to be present. The highest bidder for any of these 'properties' will be able to call on their purchase to make a personal appearance during the year.

Meanwhile our Home Counties Area Appeals Organiser, Madeleine Legg, has successfully promoted

a Theatre Party in aid of ASBAH at the Theatre Royal, Windsor. The high spot of this enjoyable evening was a performance of the renowned farce "A Bedfull of Foreigners".

More and more Student Rags are bringing to us their own unique reserves of enterprise, fun and idealism. This year, for the second year running, we are honoured to receive the support of Aber Rag, which is now firmly entrenched as Europe's premier student fundraising organisation. Additionally, we have also benefited from many other Rags in colleges large and small throughout England and Wales.

Ian Morrison Assistant Appeals Director

This summer picture recently sent to LINK shows Roy Swanick and Margaret Wheadon on their wedding day. They met while both were still pupils at Meadowside School in Birkenhead. They were engaged two years ago and last year they took out a mortgage on a neat, terraced



house which they have decorated themselves. Margaret who has spina bifida went into a clothing factory as a machinist when she left school. She managed to keep house and go to work for four months after they were married, but has now decided to be a full-time housewife. Roy works in the printing business.

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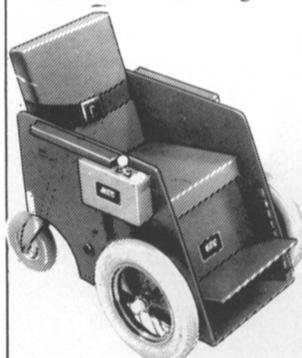
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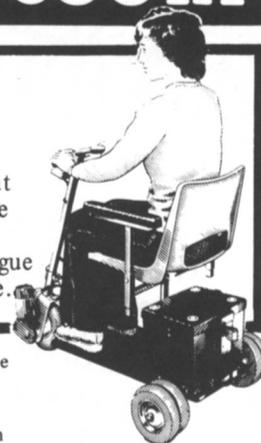
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ASBAH booklets etc...

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Your Child with Hydrocephalus,
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Little Joe (A Grandmother's story) by W. Foster ... 50p
 Information leaflets 100 for £4.00

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, Hindi, 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

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