

Link



Association for Spina Bifida and Hydrocephalus/ASBAH 10p May/June 78



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Moulded Seating : Esther Rantzen Appeal**

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Association for Spina Bifida
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Mrs S I Gearing

JUNE 4-10 is "Access Week"—
the culmination of the campaign of
the Silver Jubilee Committee on
Improving Access for Disabled
People. During this week the
Committee will attempt to focus
attention on the problems of the
handicapped. There will be awards
for local initiatives taken during
the campaign and prizes for the
winners of a competition for school
children.

But, if in one sense the week
represents the culmination of a
campaign it must also be the start
of a continuing effort, by
organisations and individuals, to
ensure that the message is not
forgotten.

Access is certainly the key to a
full life for the handicapped. At
work, in colleges and schools, and
in public places, such as leisure centres, the handicapped person can and
should be able to participate to the full if . . . If he can first get in and
second, once in, enjoy relatively free movement.

The things that bar the way are all too familiar to most of you.
Steps without handrails, narrow or revolving doors, curbs without ramps,
an absence of lifts, controls at too high a level. The list is endless. And
you know it all too well.

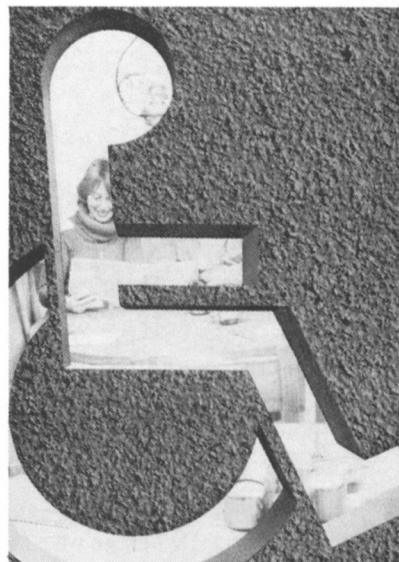
But as the Silver Jubilee Committee has been doing its best to
demonstrate—there is nothing inevitable about all this.

A simple change here; a modest expenditure there can sometimes
dramatically open up a whole new world for the disabled.

Let us be ready to challenge the authorities concerned when we find
the way is barred. A collective approach is best, so get together with
other handicapped groups to make your point. Together you will add
up to a powerful local pressure group.

We have to be realistic; we have to be practical if we are to make
progress but since it is often ignorance and thoughtlessness which are
at the root of the problem, these qualities are powerful weapons.

In National Office can help with practical advice let us know.



The new LINK

MANY apologies for the late delivery of the last two issues of LINK
which was due to production difficulties. We are now confident that we
have managed to put matters right.

We are very pleased that the new-style LINK has been so well received.
Please do write in with your news, views and letters. Items for the
July/August LINK must be with me by June 1.

Some readers have complained that this new size LINK does not fit
easily into a foolscap envelope. However it will fit one of the new larger
international size envelopes.

Editor

Cover Story

*HAPPY landings! A young sea angler, in a party of disabled schoolboys
from the Midlands, lands a large thornback skate while fishing as a guest of
the Endeavour Deep Sea Group out of Aberystwyth. This is taken from
a series of three new films under the title 'Able to Fish' which are all
about opportunities for the disabled angler. (See page 14).*

Photo Town and Country Productions Ltd.

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The reward made the struggle worthwhile

MY SON, Dennis, is a spina bifida child. He was born December 13, 1943 and weighed 6½ lbs.

The war was on and times were pretty bad. The midwife helping at the birth did not know a lot about the complaint.

I started taking Dennis to hospital, Gt Ormond Street, when he was three weeks old. He had operations, all through his school years, and he missed a terrible lot of schooling. His last operation was at the age of 24. It was a major operation and we nearly lost him. He was so ill.

In all that time he never complained. He was always laughing and making things. He likes art and is quite good at it. He learnt all this when he lay in bed weeks at a time.

I had two other children by then—a boy and a girl who were born perfect.

Scarce

Money was very scarce in those days. When Dennis was 13 years, I took him to a hospital for nervous complaints. The doctor told us he would never get any better, but he would not get worse. If he ever married he would never be able to father a child.

Well, Dennis did get married in September 1968 to a wonderful girl who loves him very much. She has such wonderful patience and understanding with him.

The most wonderful thing is that after being married for 7½ years, and trying to adopt a baby, they had a little boy of their own. He is 20 months old now and perfect in every way. Then in December 1978 they had another son—7¼ lbs, and perfect.

I had a very hard and distressing time bringing up Dennis over the years but it is a lovely feeling now to think he has grown up, married a lovely girl, and they now have two children of their own.

I hope this letter may help other parents to hope for the future.

**MRS. M. BIGROVE
STANMORE, MIDDLESEX.**

Why social workers are not all the same

MR. A. BASSETT writing in LINK (Jan/Feb. 1978) tells a cautionary tale about the labyrinth of unhelpful bureaucracy encountered when he tried to get his home adapted to provide proper facilities for his handicapped child. Almost as an aside he writes “—prior to that time we had wondered what social workers do—(we still wonder what they do)”.

As a social worker, my attention was caught by Mr. Bassett's words. Possibly there are thousands of people like Mr. Bassett who have some contact with social work, and were left wondering what it was all about.

Question

What do social workers do? It seems a plain question to which there should be a simple answer. Unfortunately, where people are involved, nothing is ever plain and simple.

I think the easiest way to illustrate the problem is to transfer the question into another (less emotive) area. Let me put the question “What do electricians do?” I would ask people to think carefully about the following situations: (a) an electrician employed by the Electricity Board, (b) one who works for a builder, (c) an electrician who works for a car manufacturer, (d) for a local council, (e) for ICI, (f) for an air line, (g) an electrician who works on an oil rig.

Now I think the problem becomes a bit clearer. All these individuals are going about the job of being an electrician—but in vastly different ways. It is this characteristic of an occupation which social workers share with electricians, with

engineers, with chemists and many others. *SOCIAL WORKERS DO A VARIETY OF THINGS IN DIFFERENT WAYS, ACCORDING TO THE SETTING IN WHICH THEY OPERATE.*

A social worker's operational field may be a civil service department, a local authority, a GP's practice, a health clinic, a general hospital, a psychiatric hospital, a school, or a voluntary society, etc. She may be concerned with under 18s, over 80s, with delinquents, unmarried mothers, or VD patients, or mentally handicapped persons, or epileptics, or homeless people, or deprived children, or drug addicts, etc. She may be involved with any one category or with the whole range. She may work in 20 square miles of densely populated metropolitan district, or a quiet holiday resort, or a dying mining valley, or in a thousand square miles of hill country.

Function

Even when we have defined the function of the particular agency where the social worker is employed, and when we have described the client groups and the topography of the area, we are still a long way from knowing what an individual social worker is doing.

There is no single answer to the question “What do social workers do?”. I can only await the reaction of your readers. If they wanted to know what one social worker, i.e. myself, does in his particular situation, I would try to describe it. There is no way I could tell them what other social workers are doing, because only they, individually, could answer for themselves.

R. J., Wilts.

Sheets put to the test

YOU MAY have seen the advertisement for Kylie Absorbent Bed Sheets in the last LINK, and if you would like more information on them you should contact Jill Vernon the Aids and Appliance Officer of ASBAH.

The sheets have been tested through ASBAH and Jill will be able to tell you more about them. They are not likely to suit all spina bifida children.

A report based on the tests will appear in a later LINK.

PHAB earns itself grant of £10,000

PHAB (Physically Handicapped and Able Bodied) is to receive, for the first time, a grant of £10,000 a year from the Department of Health and Social Security. The sum will be given to the charity for the next three years. PHAB has 200 clubs enabling disabled and able-bodied young people to meet informally on equal terms.

Irish guide

THE Northern Ireland Council of Social Service has produced a first guide to holiday accommodation in Northern Ireland. The guide carries details of holiday homes run by voluntary bodies, and hotels, guesthouses and private accommodation which are accessible. It is obtainable from The Northern Ireland Committee for the Handicapped, NICSS, 2 Annadale Ave., Belfast, BT7 3JH. Price 25p.

Access information

WHEREVER you are holidaying this year – whether at home or abroad – don't forget there may well be an Access Guide covering the area and giving a great deal of information about accommodation, access to places of interest etc. To find out if there is an Access Guide for your holiday spot contact RADAR, 25 Mortimer St, London W1N 8AV (01-637 5400).

Tyre discount

NATIONAL Tyre Service has decided to increase the discounts which it offers to recipients of the Mobility Allowance and to NHS vehicle service beneficiaries. The discount on leading tyre brands has been increased to 25 per cent and on lesser known brands such as India and Courier to 30 per cent.

Disabled people wishing to apply for these discounts must obtain a Privilege Purchase Card to present to the dealer. This is available from the Retail Marketing Dept, National Tyre Service Ltd, 80/82 Wellington Road North, Stockport, Cheshire, SK4 1HR.



A handicapped scout enjoying the pleasures of a woodland ride
Photo: Camilla Jessel

Kitchen design

A SPECIALLY designed range of custom built kitchen furniture for the disabled by Geo. A. Moore, can be bought from John Lewis, Oxford Street and Peter Jones, Sloane Square.

For a charge of £20 a representative from John Lewis will visit the customer's home to prepare a plan to an agreed budget, the £20 being deducted if the customer wishes to proceed.

Worktop heights can be tailored to suit individual needs, units pull out from under worktops for all round access, and doors spring open with a nudge from knee, elbow or fist.

Clan gathering

PHAB 1978 Family Week: The PHAB Clan Gathering is being held this year at the Trefoil Centre, Edinburgh, from August 12-19. More information from PHAB office, 42 Devonshire St, London W1.

Family Fund goes on

THE FAMILY Fund, which was set up four years ago to help very severely disabled children and their families, is to continue indefinitely, Alfred Morris, Minister of State for the Disabled, announced recently.

continued over

The Fund will continue to be administered by the Joseph Rowntree Memorial Trust and the Government has agreed to keep it at around the present level of expenditure, but with regular reviews. The Government is committed to give the fund £9.5 million to the end of 1978.

Sparkle visits

SPARKLE, the motor yacht which has been designed specifically for disabled people will be visiting Plymouth, Chichester, Newhaven and Poole this summer. Please contact Miss Holland at National Office for specific dates and the name of the person to contact for a booking. Sparkle can take parties of 12 people (10 wheelchairs and 2 able-bodied helpers). 'Sailors' should take their own picnics but drinks are available on board.

Wheelchair advice

A NEW booklet on wheelchairs has been added to the *Equipment for the Disabled* series which although produced primarily for professional workers concerned with the care of disabled people, is also of interest to disabled people. The publishers suggest, however, that professional guidance is sought before a purchase is made to ensure that the most appropriate equipment is obtained.

The booklet has two sections which contain details of both commercially available wheelchairs and wheelchairs supplied in the UK by the DHSS. Contents include types of wheelchair available, wheelchair accessories, children's mobility aids and addresses of Artificial Limb and Appliance Centres and Limb Fitting Centres in the UK and addresses of DHSS approved repairers of wheelchairs and 3-wheelers.

'Wheelchairs'—and other titles in the *Equipment for the Disabled* series—are available from the Oxford Regional Health Authority, 2 Foredown Drive, Portslade, Sussex, BN4 2BB. Price £1.50 plus post and packing (no money should be enclosed with orders as an invoice is issued).

LIFT-OFF

LIFT—the young ASBAH group—is really getting underway with many ideas for the future, but it still welcomes more members. Young people aged 13-25 with spina bifida or hydrocephalus can join . . . the more the merrier.

One of the suggestions that arose from the National Spring Conference was that LIFT members want a Conference of their own next year, perhaps with young able-bodied people to help out, and with members of ASBAH's executive there in a watching role rather than organising it.

This enterprising group of members even decided that they would like the conference to be held in Birmingham!

But that's all in the future and depends on a lot of things, not least on having enough money for it! If you would like to join LIFT or have more details write to LIFT, ASBAH, Tavistock House North, Tavistock Sq, London WC1H 9HJ.

members. It was used on Merseyside for a World Day of Women's Prayer and if any LINK members would like a copy they should write to National office.

DHSS review

DHSS wheelchair review. Do you have any comments on, or problems with, any of the following parts of the National Health Wheelchair service?

- General information to the public about the wheelchair service.
- Procedures for recommendation, selection, and ultimate prescription.
- Arrangements for supply.
- Guidance to wheelchair users.
- Arrangements for repair and maintenance of wheelchairs.
- General attention to users' needs following initial supply.

Please try to find time to write to ASBAH. Case histories are needed to convince the Department of Health and Social Security that there are problems with the wheelchair service.

Sports club

THE UNIVERSITY of Birmingham is to form a Sports Club for the Disabled which will be free to all disabled persons, whether or not they are members of the university. The normal charge to non-members using the facilities is £15 a year.

The new club is believed to be the only facility of its kind on the south side of Birmingham. Its chairman is Professor E. A. Marsland, a Pro-Vice-Chancellor and Head of the Department of Oral Pathology in the Dental School. Professor Marsland, who is confined to a wheelchair, is also chairman of the university's Committee for Disabled Members.

Birmingham University has been gradually opening up its sports facilities to various groups of disabled people over the last year—swimming, table tennis, indoor archery and weight-training are just some of their activities—but the new club also hopes to organise outdoor sports such as wheelchair racing. There is no lack of able-bodied volunteer helpers from staff and students.

Insurance discount

INSURANCE Brokers, Hartley Cooper & Co Ltd are now giving a 25% discount off the published scheduled rates for disabled drivers, insuring under their special scheme with the Shead Motor Policies at Lloyds. The discount used to be 15%.

Details from Hartley Cooper & Co Ltd, PO Box 25 Hartley House, Eaton Rd, Enfield, EN1 1NR. Information on this and other motor insurance schemes for the disabled is always available from the Mobility Adviser at RADAR, 25 Mortimer St, London W1N 8AB or from ASBAH National office.

Special prayer

LIVERPOOL & District ASBAH has sent us 'Our Lady's Prayer' which was composed by the wife of one of our Executive Committee

The largest Convention for the Disabled ever to be held in the United Kingdom, comes to Brighton!

**The Brighton Centre
and Hotel Metropole
18-21st September '78**

naidex'78

THE NATIONAL AIDS FOR THE DISABLED EXHIBITION



Photographs courtesy of Jane Radford.



& THE EUROPEAN CONFERENCE OF REHABILITATION INTERNATIONAL

Naidex '78 promises to be even more successful than ever! The response enjoyed in London during the 1977 Convention, has established this specialised Exhibition and Conference as the most important event in the calendar for Industries and Associations involved with Disability and Rehabilitation of the Disabled.

In order to meet the demand for increased bookings in 1978, the Exhibition and Conference moves to the Brighton Centre and Hotel Metropole on the south coast of England. The accommodation in these two centres is both plentiful and purpose-built thus creating an ideal forum for Delegates, Exhibitors and Visitors.

Concurrent with the Exhibition will be the European Conference of Rehabilitation International, whose theme for 1978 is 'Disability in the Family'. Subjects to be covered in the Conference will be; Congenital, Neurological, Traumatic and unstable disabilities, Blindness, Deafness and Mental Handicap.

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

To all persons involved in the care and welfare of the Disabled, Naidex '78 will prove to be an Exhibition and Conference of immense importance and value. For full details please contact the Organiser.

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TOWARDS INDEPENDENCE

A RECORD number of people attended ASBAH's Spring Conference this year. It was good to see so many young people with spina bifida, professionals, parents and members of local associations as well as staff from National ASBAH and one or two visitors from overseas.

Altogether 170 people gathered together at Digby Stuart College, Roehampton, South West London on the rather cold, weekend of 7-9 April.

The happy, relaxed atmosphere of the conference was due largely to the efforts of the Director of Queen Elizabeth's Foundation for the Disabled, Mr Robin Smith, who acted as Chairman.

The first evening started in light-hearted mood with a speech by Mr R. Hadingham, Chairman of Slazengers and Chairman of SPARKS (Sportsmen Pledged to Aid Research into Crippling Diseases) which raises money by staging sporting events in which famous sportsmen and entertainment personalities take part. Apart from sending most of the money to Action Research for Crippled Child SPARKS also runs 'Sparkle', the sailing boat adapted for wheelchair sailors (see page 6).

Sports

Mr Hadingham and the following speaker, Mr Norman Croucher, were both on the sports sub-committee concerned with Lord Snowdon's Report into the integration of the handicapped.

Mr Croucher, a determined and resourceful young man with artificial legs, showed how he regained his independence and took up climbing after an accident 18 years ago when he was run over by a train, losing both legs below the knees.

He has achieved two goals—walking from John O' Groats to Lands End and becoming an expert mountaineer, climbing a number of difficult peaks including the Matterhorn.

He spoke of the importance for



SPARKLE

the disabled of having a sport or leisure activity, whether it be a sport or an interest such as chess or listening to music.

Mr Croucher also stressed the need for integration in sport so that a disabled person could compete (or just participate) with able-bodied people, not only with other disabled.

Some of his slides were taken at adventure centres in this country where disabled and able-bodied can have a go at different activities such as canoeing, rock-climbing, field studies . . . In particular he mentioned the newly opened Calvert Trust Adventure Centre in the Lake District (a write-up appeared in the last LINK).

Mr Croucher's talk opened up the exciting possibilities and challenges awaiting those people who are willing and able to get involved with some kind of leisure activity.

■ One of Mr Croucher's books, recently published is 'Joining-In', a Disabilities Study Unit publication which looks at the whole question of integration in sport, and which includes information and useful addresses for many pursuits. £1 from DSU Wildhanger, Amberley, Arundel, West Sussex BN18 9NR.

■ For more information about courses at adventure centres contact Mr H D Macfarlane at ASBAH National Office.

QUOTE

**'You have to fight for yourself. DRO's and Careers Officers are a waste of time'.
A parent talking about employment prospects.**

Integration: What it adds up to

"INTEGRATION is not being treated differently from the majority of people because of a physical, sensory or mental malfunction. It is being allowed to behave—and misbehave—as the non-disabled do".

This was the definition given by Mr Duncan Guthrie now Director of the Disabilities Study Unit and renowned for his work in many different organisations concerned with the disabled, particularly the National Fund for Research into Crippling Diseases.

Mr Guthrie was instrumental in persuading the National Fund to establish the working party on Integrating the Disabled, which became more commonly known as the Snowdon Working Party when Lord Snowdon agreed to act as Chairman.

Integration

The Snowdon Working Party broke down the problem of integration into seven arbitrarily selected areas: education, employment, housing, community and personal relations, transport, public buildings, sport and leisure.

Touching briefly on the last category Mr Guthrie mentioned the success the Working Party had had in persuading the newly opened National Theatre to improve its access facilities for the disabled which were 'grossly inadequate'.

Mr Guthrie stressed that the beginning of integration must come at school.

"I have been an advocate of integration in schools, but unfortunately there has been a resistance from the Government".

He gave a hint of a gleam of hope when he mentioned the possibility of a resource centre starting in this country modelled on the lines of one in Sweden which had so impressed him. The Swedish centre, used by teachers at normal schools, helped them to understand more about disabled children and the equipment and teaching techniques which were available to allow most disabled children to be absorbed into an ordinary classroom. It had proved invaluable to teachers who were willing to take in a handicapped child but were uncertain and largely ignorant of how to cope.

Attitudes

Mr Guthrie suggested that maybe government attitudes were beginning to change. "Even the Department of Education and Science said 'If the handicapped and the normal are to understand one another and live together in the adult world they should not be separated during their more formative years'".

He understood that it was not easy to integrate the disabled into schools, particularly in existing buildings. New purpose-built schools offered exciting possibilities, and he mentioned a new comprehensive at Angmering, Sussex of which he was a governor. Between 75-100 disabled students would soon be absorbed.

"We are all anxiously awaiting the findings of the Warnock Committee" said Mr Guthrie. The Committee, set up over 2½ years ago, to look at special education was due to report now, and he hoped it would have new and positive ideas and suggestions for integration, and that the report would not be put on a shelf to gather dust.

"If integrated education is successful it must lead to integrated employment. To achieve this special support for the disabled worker will

be essential, whether it be in modifying jobs or premises, re-arranging work schedules or supplying special aids and support services". Support could often mean simple human help—someone to read a report to a blind person, someone to push a wheelchair etc.

"Getting to and from work can present difficulties. The Employment Services Agency has powers to help with fares to work, but at present this kind of help is given on a very limited scale. It must be extended.

"Finally it must be remembered that, in work, integration is dependent upon the payment of *real* wages"—take-home pay must be large enough to provide sufficient incentive to seek employment.

Mr Guthrie quoted from Professor Ralf Dahrendorf's 1974 Reith Lecture. 'Survival is not enough; what matters is a life worth living'.

This, he said, was particularly true in the area of community and personal relationships.

Mr Guthrie spoke of the immense help that could be given by volunteers particularly in the home when it came to tasks such as helping to wash the disabled person, or helping with his or her toilet. These were not difficult tasks—although they were distasteful to some people—but he said it was astonishing how many kind people there were willing to help in this way and so enable the disabled person to stay in the community.

Mr Guthrie challenged the present work ethic concept and wondered whether some severely disabled people should be helped to enjoy reasonable leisure activities instead of being urged—perhaps against their inclinations—to work at dull, repetitive tasks.

He finished by saying he hoped that research would concentrate more on the problem of incontinence which he felt was the greatest single drawback to any disabled person enjoying an independent and integrated life.

Dignity comes along with independence

MRS HILARY GATFIELD, who spoke later, also emphasised the loss of dignity which a handicapped person suffered through being unable to control incontinence properly.

Mrs Gatfield, Manager of the Children's Division of Downs Surgical, spoke of the independence week's organised by ASBAH where she had helped youngsters to be independent in handling their appliances and coping with their own toilet.

She made a plea to parents to encourage very young children—from about 5 or 6 years—to learn to manage appliances themselves. If they could get accustomed to the feel of it all at this age it was much easier for them to accept, and far less embarrassing than having to teach them when they were teenagers. Often young people didn't really like their mothers helping them with intimate tasks like this, but didn't like telling them.

Mrs Gatfield said that appliances had considerably improved over the last ten years and there was now something to suit almost everyone. Self-catheterisation was growing in popularity in this country, and she hoped that Downs would soon be producing their own catheters. At the moment they are imported from the USA where catheterisation is widely practiced.

She said that if anyone had any problems she would be only too happy to help, and Downs London Showroom (32 New Cavendish Street, London W1M 8BU tel: 01-486 3611) was open so that personal callers could be helped and advised with appliance problems and fitting.

FACTS

- In 1970 the number of registered disabled was 404,800 and this had risen to over 915,000 by March 1977, and is probably nearer the 1 million mark now.
- House adaptations to the homes of disabled people rose from 28,000 in 1973 to 49,000 in 1976.

■ 'Ostomy and Incontinence Aids' is Downs' catalogue and can be obtained by writing to Downs Surgical Ltd., at the London Showroom (address above) or at Head Office, Church Path, Mitcham, Surrey, CR4 3UE. Tel: 01-640 3422).

Adolescents need to build identity

THE IDENTITY crisis—the need to look closely at where we were going and who we were—applied not only to the individual handicapped person, but also to organisations like ASBAH and the Spastics Society, said Miss M. R. Morgan, Controller of Personal Social Services for the Spastics Society.

She said that ASBAH and the Spastics were started originally by parents, and now they both had to face the question 'Should we still be looking at the needs of the handicapped with parental eyes? What about the handicapped themselves? Where do they fit in terms of planning and total organisation?'

Miss Morgan welcomed LIFT (Young ASBAH) and hoped it would forge ahead and give voice to the ideas and views of its members.

Her speech concentrated mainly on the difficulties of the adolescent stage and the confusion of coming to terms with one's own identity and one's situation. She felt it was vital that young people were able to mix with as wide a group of people as possible, particularly with others of their own age. They need to test out relationships and get over disappointments like anyone else.

It was very difficult for a person, physically dependent on others, to be rebellious. For instance, if handicapped, it was difficult to physically run out of a room and slam the door, or go shopping alone and waste money on unsuitable purchases. She felt that parents were sometimes not aware of how important this stage was, and often resorted to the easy and less exhausting way out—keeping the young person under their control.

QUOTE

'I labour under a built-in disadvantage, that of being a bureaucrat'.

Mr G. Bebb, Assistant Secretary, DHSS.

FACTS

- Households receiving personal aids and equipment increased from 118,000 in 1973 to 196,000 in 1977.
- In 1977, 73,000 telephone rentals were being paid compared to 29,000 in 1974.

Adolescents needed to feel respected and valued, and appearance and dress were an important aspect of this.

"One of the problems is also how we can help other people to understand how they can make relationships with someone who is handicapped" she said.

One of the constituent parts of being independent was job and economic independence. From her experience she believed that many people got great pleasure and satisfaction from carrying out routine, mechanical tasks which others might consider boring. It was important to feel one was able to contribute in some way.

"We must also go on fighting for young people to set up their own homes, she said even though it is much cheaper for the country to keep them at home. "I believe that everyone has a right to move away from the family nest".

The Act: On the whole it's been good

"The Act has helped create a climate of opinion which has made handicapped people a great deal more articulate . . . but in common with social legislation generally, it will certainly not match the expectations of every disabled individual, particularly during a period when the rise in the standard of living has been modest compared to the rise in expectations".

Mr G. Bebb, Assistant Secretary, at the DHSS, was speaking about the Chronically Sick and Disabled Persons Act. He explained the working of the Act and said that although he realised there were many complaints he felt that, on the whole, it had had many good results, many of them unquantifiable but related to improvement in attitudes to the disabled.

He said it was vital that local authorities should fulfill their duties

under the Act and identify the number of disabled in their area. Once the real need was known then the Department could get down to the real task of helping.

Child benefits if parents get early aid

"MY EXPERIENCE leads me to believe that there is a better chance of a handicapped child facing life, after school, in an emotionally adjusted frame of mind if the parents have received ongoing counselling and help from the very moment that the baby was known to be handicapped" said Mr J. Garrett, former Headmaster of a special school.

He said that the very earliest attitudes of parents, professionals and society have a profound effect on the child's developing personality.

A child must be encouraged to be mobile, because lack of mobility restricted all important experiences. Confidence—the reward of success—was crucial, as was independence, privacy, respect from others, and an experience of forming relationships with others, including those of the opposite sex.

Mr Garrett felt parents and young people had to be realistic, and that they should also be wary of advice from too many groups of idealists, and theorists.

Adolescence, said Mr Garrett, was growing up and losing the family ties while at the same time forming new ties and relationships.

QUOTE

'It seems to me that society at large adopts the dubious stance of the person who trips you up and then sympathises with you because you have fallen over'.

Mr Bebb speaking about lack of access for the disabled.

The younger people will have great memories of the Conference thanks to the good time they were given by a local group of Extension Scouts who organised activities and showed them some of the sights of London.

On the question of employment, Mr Garrett said that this could be an inappropriate goal for a very severely disabled person, and that young people needed to be encouraged to learn to use their leisure well. A school needed, perhaps, to teach the young person to get used to routine jobs as these might form the basis of his early stages.

Before getting a job the school-leaver had to be able to get himself up in the morning, travel to work and arrive punctually. These sounded like simple tasks but were often neglected. He or she also needed to be able to cook, and be aware of how to dress well, and be well groomed. Parents of a handicapped child needed to be as pestering and as "nasty" in these matters as those of a normal child.

Standards

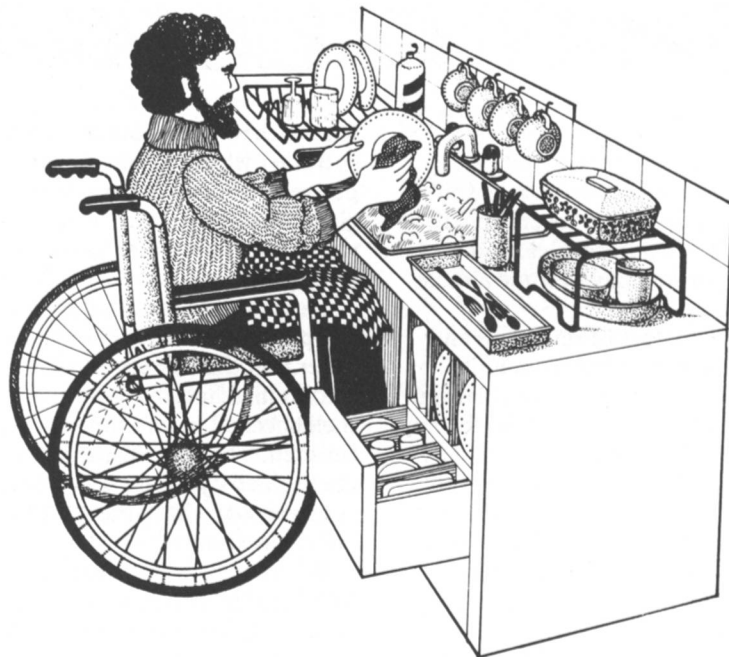
When asked, during questions, if he considered that educational standards were as high at a special school as at a normal school, Mr Garrett said he felt that perhaps there was too much emphasis in a special school on caring, rather than on education.

He felt that the solution—one which was practised at his former school—was to educate the pupils at the special school for the first three years, giving them care, and help—in other words 'weaning them' and then send them to the local comprehensive school to take the third year again. Repeating this year usually gave them confidence, and made it easier for them to continue at the ordinary comprehensive for the rest of their school life.

QUOTE

'The secret of success is pressure locally. Local groups concerned with the handicapped should get together and press for change'.

Mr Bebb.



Independence in the kitchen. Drawing by Jan Churcher from "Handicapped at Home", Sydney Foott Design Centre. Price £3.75.

Automation may help job hopes

DURING an interesting talk about ways of helping the disabled to be rehabilitated into society, Dr J Somerville—Medical Director of Camden Medical Rehabilitation Centre—suggested that in future, with increased automation and the need for more unskilled workers, there might be better job prospects for the disabled than in the past.

FIRE REGULATIONS

Mr Robin Smith, Conference Chairman expressed concern that fire regulations were so strict that they severely restricted access facilities for the disabled.

'If anyone has examples of local buildings where fire regulations appear too extreme, could they let their local DHSS know,' said Mr Bebb (Assist. Sec. DHSS). He felt that there should be some compromise between the two, and only by referring to individual examples could progress be made.

Discussion Points

ONE or two of the main points which came out of the discussion groups: **MOBILITY** was welcomed, but there was real concern about the quick withdrawal of the invacar which left stranded the 16-17 year olds. **ASBAH** was asked if it could take up this matter again.

The group felt this was another example of an official Report being ignored—in this case the Sharp Report which recommended the gradual phasing out of invacars and replacing them with adapted vehicles. It was suggested that parents could look to the future and invest their child's mobility allowance so that a

capital sum was available when the child was 17 to purchase an adapted vehicle.

THERE should be more emphasis on helping and advising hydrocephalics.

THE VALUE of the independence weeks organised by ASBAH was realised, but the cost was proving prohibitive to some parents.

Could local groups or individual money-raising efforts help.

ALTHOUGH undoubtedly some people would never be able to walk, many of the younger people at the conference felt that the greatest encouragement should be given, at an early age, to get them out of wheelchairs.

SITTING COMFORTABLY

UNEQUAL muscle pull or malformation of the vertebrae, caused by conditions such as spina bifida, can produce severe spinal and thoracic deformities, and normal sitting may become almost impossible.

There is a loss of sensation and no discomfort is felt from a sitting posture which impedes circulation. If this posture is maintained for any length of time, pressure sores may develop, which can take weeks to heal.

In many instances these localised high pressures can be distributed by cushions of various designs, using materials such as polyether foam, polystyrene beads, gel, or water. These cushions conform to the body shape in order to increase the area of contact and so distribute and reduce the supporting pressure.

Service

For very severe cases, a seating service has been developed at Chailey Heritage, based on a design of moulded seat which distributes pressures over the whole seating area, and provides comfortable postural support and protection. These seats are prescribed at a weekly seating clinic, to which the patient is referred by his consultant or GP.

The patient is positioned correctly on a bag of polystyrene beads so that the best position is obtained for the chest for ease of breathing, and the eyes and hopefully, the shoulders, are held in a horizontal plane. When the optimum position is achieved, the bag of beads, which is in close contact with the patient, is evacuated by means of a vacuum pump and this consolidates the beads maintaining the shape of the patient.

The patient can remain seated in this shape for as long as necessary to establish that there is no discomfort or reddening of the skin, a period of twenty minutes being an average time.

Having ensured that the best seating position has been obtained, the patient can be removed from the bag and a plaster of Paris impression made of the patient's shape. The plaster impression is then used as a mould to vacuum

form a thermoplastic seat shell with soft liner which accurately fits the patient's body contours. It also gives the required postural support whilst alleviating high pressures on bony prominences.

The patient sits in this shell whilst it is positioned on its base board in order that the correct attitude may be obtained and the fit of the shell checked before the seat is finished. The correct attitude is maintained by a base unit which is constructed to hold the shell safely on its base board.

Where the patient's lower ribs fold over the pelvis, some form of padding is introduced to prevent the bones rubbing against each other. It is often possible to straighten the spine manually and hold it in this position with the moulded seat.

It is accepted that a moulded seat cannot correct deformity, only maintain the patient's present state and maybe prevent further deterioration. Straps are added to the seat to hold it in the wheelchair or car seat and also to hold the patient. Since the moulded seat has a flat smooth base it can be used at home or in the car without damaging upholstery.

Thanks are due to Roy Nelham, Research Engineer at Chailey Heritage, for his help in preparing this article. For further information on seating, send for a booklet entitled "Sitting Comfortably". Price 20p from: Chailey Heritage, North Chailey, Nr. Lewes, Sussex (Tel. Newick 2112 ext. 99).

JILL VERNON



Example of moulded seating.



A child who would benefit from moulded seating.



The child is fitted for her seat.



... and now a more comfortable seat.

SOMETIMES it is relatively easy when you know how. But sometimes it seems impossible to get hold of even the most simple advice. So, from time to time, LINK will identify useful sources of information

Films open up whole new world

A FILM show can provide a stimulating, educational and enjoyable evening for a local association, or group of younger people.

There is a wide variety of films, and slide programmes available for hire.

There are films specifically about spina bifida, films about individual organisations, homes and schools, and more general films on subjects such as human growth and reproduction . . .

LINK hasn't the space to list all the films. But if you write to the following addresses you will have at your fingertips all the details about the many films available: CONCORD FILMS COUNCIL, 201 Felixstowe Road, Ipswich, Suffolk, IP3 9BJ. Send £1 for catalogue. Concord is a charity, and its film library is the largest educational film library of its kind, with films capable of keeping a local association interested and stimulated for many years to come! RADAR. (Royal Association for Disability and Rehabilitation), 25 Mortimer Street, London W1N 8AB (Tel: 01-637 5400). Ask for the list of 'Films on Rehabilitation available on loan from British Organisations'.

TOWN & COUNTRY PRODUCTIONS LTD., 21 Cheyne Row, London SW3 5HP (Tel:

01-352 7950). The films are mainly about sports and physical recreation for the disabled. Ask for their full list of official films.

• There is, too, the film 'What Shall We Do Tomorrow?' made for Mansfield and Worksop ASBAH, and available from the Secretary, Mrs E. Freeman, 23 Melbourne Street, Mansfield Woodhouse, Notts. Tel: Mansfield 26860. Hire: £3 plus carriage and compensation. The film deals with the problems and achievements of spina bifida youngsters with comments from parents and teachers. It also shows some local money-raising events. Colour, 16mm, 22 mins. (See also P14 about new fishing films).

College welcome for the disabled

HUDDERSFIELD Technical College is offering a year long course for the disabled school leaver. It will allow the student to continue his education in such subjects as English, maths, and general studies, but will also give an introduction to vocational education/training.

The students can spend six hours a week on studies of their own choice. These can be chosen from the many courses offered.

The College has also published an excellent handbook for the disabled student detailing access facilities which, it hopes, will encourage more to enrol for courses.

Further information can be obtained from Mrs J. Taylor, Room 419, Huddersfield Technical College, New North Road, Huddersfield. Tel 36521 Ext. 206.

THE Disabled Living Foundation, 346 Kensington High Street, London W14 8NS. Tel: 01-602 2491 has a permanent display of a very wide range of aids and equipment. Individuals or groups of disabled people are very welcome to visit—phone them first for an appointment.

There are also aids centres now in:

Birmingham: Disabled Living Centre, 84 Suffolk Street, Birmingham B1 1TA, Tel: 021-643 0980.

Liverpool: Merseyside Aids Centre, Youenes Way, Liverpool L14 2EP, Tel: 051-228 9221.

Newcastle: Newcastle Aids Centre, Mea House, Ellison Place, Newcastle upon Tyne, Tel: Newcastle upon Tyne 23617.

Reading list

Aids and Equipment—60p + postage from ASBAH.

Aids for the Disabled—free from your local Social Security office, or by post from: DHSS, Physical Handicap Branch, Alexander Fleming House, London SE1 6BY.

Coping with Disablement—£1.75 from bookshops or by post from: Consumers' Association, Caxton Hill, Hertford SG13 7LZ.

This book gives practical advice on how to cope with a wide range of everyday problems, and also includes descriptions of useful aids etc.

Directory for the Disabled—by Ann Darnbrough and Derek Kinrade—£4.25—published by Woodhead-Faulkner Ltd.

A very comprehensive book giving all kinds of useful information for the disabled, and including a chapter on the provision and availability of Aids.

You should always ask for professional advice when considering any aid or piece of equipment.

Equipment for the Disabled—£1.50 + postage for each booklet from: Equipment for the Disabled, 2 Foredown Drive, Portslade, Sussex BN4 2BB.

A series of booklets, intended for professionals, giving guidelines for the selection of equipment, and details of manufacturers. Titles are:

Clothing and Dressing for Adults
Communication
Disabled Child
Disabled Mother
Hoists and Walking Aids
Home Management
Housing and Furniture
Leisure and Gardening
Personal Care
Wheelchairs and Outdoor Transport.

All of these publications would be useful for a local Association library. (If you haven't already got one—start one now!)

Esther's TV appeal raises £36,823



THE entire appeals department, for the fortnight following Esther Rantzen's BBC TV Appeal, was scarcely visible beneath the floods of mail coming in each day. Excitement mounted as the daily total of donations was counted and banked.

It was a chastening experience in many ways: the letters were often deeply moving and many people had obviously made a personal sacrifice to contribute. I would guess that the majority came from old age pensioners, many were from children who sent their pocket money or the contents of piggy-banks.

At the time of going to press the appeal has reached the magnificent sum of £36,823 and we are deeply grateful to Miss Rantzen for her wonderful appeal, to the BBC for granting this facility, and to the hundreds of donors who responded so very generously.

There can be no doubt that the courage of the children who were interviewed touched people's hearts and I hope it will warm our parents' hearts to know that so much goodwill exists.

KATE WHITE

HOW TO GET HOOKED ON ANGLING

THREE films under the title "Able to Fish" have been sponsored by Midland Bank for the Disabled Living Foundation. The Foundation, which has produced the films with the co-operation of the National Anglers' Council, aims to show that fishing can become the outdoor recreation of the handicapped man, woman or child.

The three films have been made by Town and Country Productions and each deals with one of the three branches of the sport—coarse fishing, game fishing and sea fishing. They illustrate how even the most disabled people can enjoy the sport, and they may encourage public authorities to provide more facilities. In many cases only good access and hard standing is needed.

The films

- Film No. 1. 'Coarse Angling' (34 mins) Commentator Richard Baker.
- Film No. 2. 'Game Fishing' (32 mins) Commentator Leonard Parkin.
- Film No. 3. 'Sea Angling' (23 mins) Commentator Bernard Cribbins.

It might be a good idea to have a member of a local angling club to come along and talk about local facilities.

Each film can be hired by making written application and enclosing a cheque for the booking fee of £5.40 (inclusive of VAT) to: Town and Country Productions Ltd., 21 Cheyne Row, London SW3 5HP. There is a holding fee of £4.32 for every subsequent day that a film is retained. If a speaker is required please indicate this when making the booking. The films must be shown on a 16mm projector by a qualified projectionist.

A book "A Guide to Fishing Facilities for Disabled Anglers" has been produced by the National Anglers' Council. It puts the handicapped in touch with existing facilities and lists more than a hundred fishing locations. It also carries information about special equipment. Price £1 including postage from: National Anglers' Council, 5 Cowgate, Peterborough, PE1 1LR.

CLASSIFIED 'ADS'

THE CLASSIFIED advertising section is something new for LINK 'and we hope that your 'ads' will come pouring in!

It will take in 'ads' not only for Holiday Accommodation, but also articles For Sale or Wanted, For Hire etc. Let us know what you want to advertise and we will let you know if you can!

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

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

HOLIDAY ACCOMMODATION

BASHLEY PARK, New Forest: Two bedroomed chalet, 4/6 berth. Telephone: evenings only Portsmouth 68193.

CHRISTCHURCH: 6/8 berth Caravan. 1 mile from sea. Near New Forest. Club House. Mrs D. Collier, 2 Barnard Close, Nythe, Swindon.

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

MABLETHORPE: Two well-equipped chalets, self contained, 6-berth. Situated at Golden Sands Estates, Mablethorpe. Details: Mr B. Guest, 57 Bloxwich Lane, Walsall.

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

PRESTATYN: Two well equipped 6-berth caravans. £25 (off peak £12.50). Mrs Taplin, Colonial House, 63 Corporation Street, Manchester M4 3DT.

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

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

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

FOR SALE

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

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DISTRICT ADVERTISING COMPANY, EMI Elstree Studios, Shenley Rd, Borehamwood, London WD6 1JG offer a special service to charities. They produce telephone/address books free-of-charge, for fetes, bazaars . . . ; fund-raising charts with pockets for donations for pubs, restaurants, canteen notice boards, or hospitals clinics etc; programmes for charity matches etc. For details write to Mr J. A. Alter.

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

All available from Appeals Dept.—postage extra.

The Appeals Dept. carries a range of fund-raising items.

ASBAH booklets etc . . .

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

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



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