

Link



Association for Spina Bifida and Hydrocephalus/ASBAH 10p Mar/Apr 79



**Job
Schemes**

**Access:
Which
Way
Now?**

**YOUR
RIGHTS**

**Importance
of
Independence**

REMAP

**Literary
Dinner**

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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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CONTENTS

Pages
4 News
5 Round-up (plus Five Oaks)
6 Job introduction and job creation
7 Access Report
8/10 Your Rights (Part 1)
11 The Importance of Independence
13 Aids and Equipment
14 Appeals—(Literary Dinner)

ON PAGES 8-9 in this issue of LINK we take a look at some of the benefits designed to raise a disabled person's income to a minimum tolerable level. There are others, and we will be looking at some of them in the next issue of LINK. Although the sums of money involved are small, the number of benefits are many and varied. And if one concedes that this multiplicity of aid is the product of a caring society, one would have to add very quickly, it is also the product of a confused society and, not surprisingly, the end product is one of confusion.

In fact it is all rather like a cruel game of snakes and ladders. Up a benefit ladder here. Down the snake of non-entitlement there. Happily the analogy does not quite stand up since the rules do not actually allow you to end up worse off than you started.

However there is a strong element of chance in that two equally severely disabled people may be entitled to different total amounts of income. (A throw of the dice?). For example most ex-servicemen injured in war are entitled to several kinds of income benefit, but others—like most disabled married women under pension age—are entitled to none or only one.

Such comparisons are, of course, invidious. But then so is a system that imposes the distinction.

It's not hard to see how the problem has come about. The system has grown up piece-meal, with new measures being passed as wider and more varied needs have been acknowledged.

Each new measure has been embarked upon with the best of motives, but, with one or two exceptions, each has had to be hedged about with safeguards and qualifications to ensure that one group of beneficiaries (from the same sources) did not get ahead of another.

And at the same time there has been an increase in the complex language, paperwork, rules, regulations and codes which accompany the benefits.

Bemoan it though we may, the system is there, and has to be tackled, because it does contain the wherewithall to provide the disabled with a minimum income. The guide which starts on page 8 is designed to give some help in tackling it; the Disability Rights Handbook for 1979—on which LINK'S short guide is based—will give even more help.

But while we tackle it let's continue to hope for, and argue for, a system which gives disabled people a sum of money to replace lost earnings and a further allowance to cover the extra costs which are a direct result of disability. It should be a straight payment, made as of right, and unaffected by other income. Individual need should be the only governing factor. (See also "Supplementary Benefit is no Answer," page 4.)

COVER STORY

CABBAGES or sprouts today? Cathy learns how to cope with the range of goods confronting shoppers on supermarket shelves. Cathy, accompanied by Jan Tomlinson (Young ASBAH Officer), was on a shopping expedition from Five Oaks where Cathy and other young people were on an ASBAH Independence Training Week.

For details of this year's Independence Weeks see page 5. The importance of teaching children how to cope on their own is the subject of an article by social worker Niamh Murray on page 11.

Photo: Len Hooper

LINK: The last date for material for May/June LINK is April 1. Write to Mrs Susan Gearing, Editor, LINK, at ASBAH.

The yearly subscription for LINK (UK) is £1.15, which includes postage. While every care is taken to ensure the accuracy of information published in LINK the publishers can accept no liability.

THE DISABLEMENT Income Group (DIG), in commenting on 'Social Assistance'—the DHSS Review of the supplementary benefits scheme—concludes that the scheme cannot be significantly simplified without serious injustice to disabled people.

DIG argues that the needs of disabled people can only be properly met by a two-component National Disability Income. This would be made up of an incomes maintenance element, to replace lost earnings, and a disablement costs allowance, to recompense the many unavoidable extra costs which are a

direct result of disability.

DIG has constantly argued that disabled people should not have to depend on the means-tested supplementary benefits scheme, which was never designed to cater for those with long-term disability.

DIG feels that no good can come from any review of the supplementary benefits scheme undertaken, as this review was, within the constraint of 'using existing resources more

effectively'. Changes resulting from such a review merely shuffle existing inadequate resources from one person in need to another and will lead either to severer hardship for disabled people or to hardship for others.

A full report of DIG's comments on the DHSS Review can be obtained from Mr Peter Large, MBE, 14 Birch Way, Warlingham, Surrey, CR3 9DA.

Supplementary Benefit is no answer

Wanted! Some handymen

A TEAM of area handymen to assist with house adaptations and provide special aids is one suggestion outlined in a report issued by Gloucestershire's Social Services Department. The report is based on research into services available to the disabled.

The Department found that a major difficulty in getting house adaptations done was in obtaining estimates from builders willing to carry out minor alterations such as installing a handrail. Special area handymen could carry out such simple, but very essential, work quickly and efficiently.

The report highlights a number of other problems and suggest possible solutions. Services for the Physically Handicapped—Gloucestershire County Council Social Services Dept is obtainable from the Social Services Unit Dept. of Social Administration, University of Birmingham, PO Box 363, Birmingham, B15 2TT.

Watch out for TV Link

LINK is the only regular television programme for disabled people and is well worth watching. It is screened fortnightly on Sunday mornings around 11 am on Grampian, Tyne Tees, Border, Scottish, Ulster, Westward, ATV and London Weekend Television.

Lord Mayor backs Motability

SIR Kenneth Cork, GBE, the Lord Mayor of London has chosen Motability as the Charity of his Year. This will undoubtedly give a major boost to Motability's fund-raising drive and its aim that, within five years, every disabled driver and passenger who needs a car should have one.

In order to achieve this aim, Motability needs, in its first crucial years, to raise £1½ million a year from private enterprise.

Through Motability, disabled people can use their £10 weekly Mobility Allowance to lease a new car over three or four years. In addition they are asked to contribute a further sum towards the cost of most makes of car involved in the scheme.

However, in cases of hardship, Motability can use its charitable 'wing' to make up the difference between what can be afforded and what the car actually costs, including necessary adaptations. It can help, too, with the cost of driving lessons.

Motability's main financial burden will be borne in the first years, after that the task will be limited to dealing with new cases as they arise and the replacement of vehicles at the end of their leasing period.

Mobility Allowance age raised to 75

DISABLED people are to be allowed to keep their Mobility Allowance until they reach the age of 75 instead of losing it at retirement age. In addition, disabled women will be able to qualify for the allowance up to the age of 65 instead of 60 as at present. This decision was announced in the House of Commons in November and legislation will be passed during this Parliamentary session.

Disabled people will not be affected by the news immediately as, because of the phasing in procedure, nobody receiving the Allowance has yet reached retirement age. However this decision will please all those who have recognised the unfairness of withdrawing this benefit at a time when it would be likely to be needed the most.

Access to the Netherlands

AN ACCESS map to the Netherlands, for the benefit of the disabled holidaymaker, is now available from: the Nederlandse Vereniging voor Revalidatie, Postbus 323, 3500 AH Utrecht, The Netherlands.

Libraries— too often a closed book

A RECENT report 'The Libraries' Choice' calls for public libraries to be made as fully accessible as possible to the physically handicapped. The report claims that library facilities are being enjoyed by too few disabled people, and it recommends that the authorities should try and extend their 'outreach' provision (mobile services and special deliveries) to reach more housebound and disabled readers. The report is the result of a working party set up by the Library Advisory Council, and is obtainable from Government bookshops, £2.25.

ASBAH goes North with NAIDEX

ASBAH will be having a stand at Northern NAIDEX and Jill Vernon, the Aids and Appliances Officer will be there to give advice on equipment and special aids. The Exhibition (a smaller version of the London NAIDEX to be held in November) is being combined with the British Association of Occupational Therapists' Annual Conference in Harrogate, 17-19 May. (See back page of LINK for more details).

It's holiday time again

THE unique annual holiday guide, Holidays for the Physically Handicapped 1979, produced by RADAR, can be bought from branches of W. H. Smith & Son, price 75p, or direct from RADAR, 25 Mortimer St, London WIN 8AB. £1.50 to include post and packing. It lists all types of accommodation indicating accessibility, special facilities, etc and it also contains a section on activity holidays, and advice on foreign travel.

● If any LINK readers want suggestions for suitable holidays, Beverley Holland, Information Officer at ASBAH will be glad to help.

Correspondents needed

WHAT LINK needs is a regular and reliable band of local correspondents. It's the best way to secure a flow of news and views. It also keeps the magazine abreast of local opinion.

Some Local Associations are better than others when it comes to keeping us informed. Why don't we put the whole business on a slightly more official footing?

Would each Local Association consider appointing a LINK correspondent to send in regular news, views, press cuttings and

pictures? Perhaps you would put it on the agenda at meetings.

Remember LINK exists to serve as a form of communication between Associations and even if your activities seem commonplace to you they may be news to others. Of course I cannot promise to publish everything, but I will do my best.

Exchange holidays appear to be very much in fashion at the moment, and I would be pleased to receive an article from anyone who has recently been on such a holiday.

Susan Gearing Editor

News from Five Oaks

Five Oaks.



THE YORKSHIRE dales around Ilkley make an ideal holiday centre and at Ben Rhydding is ASBAH's home Five Oaks. Here children and young people with spina bifida and hydrocephalus can enjoy holidays, independence training weeks, or find a long-term home. school holidays. There is accommodation for 18 including eight long-term places. There are also two day places. The spacious house, once a family home, stands in beautiful grounds and has facilities for all kinds of activities.

The qualified staff are experienced in all aspects of care and recreation and a nurse is on duty for part of each day and always at night. Now

there is also a full time qualified officer to plan outdoor and indoor recreation and arrange outings.

The fees—which have remained the same for over two years—go up from April 1 this year to £95 per week. This is still well within the scales charged by local authorities and ASBAH hopes that this unavoidably sharp increase will not present too many problems.

Special terms will be available for school groups, accompanied by staff.

Financial help is available to cover the cost of a stay at Five Oaks. No-one has ever been refused a holiday because of the cost.

For more information contact Miss Pat Silverthorne at ASBAH.

Conference: A life to be lived



A reminder of last year's Spring Conference at Roehampton, London . . . archery on the lawns in front of the college.

LINK looks forward to being at ASBAH's Spring Conference, which is being held this year at Bath University 6-8 April. The title has been changed to "A Life to be Lived".

The Conference is ASBAH's biggest social occasion of the year, and it gives a unique opportunity for talking to others in similar situations, and people who may have been able to resolve problems that are now confronting you.

The Conference this year will allow much more time for discussion than in previous years.

MSC money can help put local ideas into action

YOU MAY be aware that the Government has provided considerable sums of money to extend schemes for unemployed young people, following on from the Job Creation Programme.

These schemes are being organised by the Manpower Services Commission (MSC) Special Projects Division.

This is a separate section within the MSC, the other sections being the Employment Service Agency, which is responsible for Job Centres and the Disablement Resettlement Service, and the Training Service Agency, which provides re-training for unemployed people and vocational courses at training colleges for the disabled.

The Special Projects Division has funds to organise programmes for the next five years, during which time a "bulge" of young people will be leaving school. The MSC hopes to provide something for all young people, including those who are handicapped or disadvantaged in other ways.

Before I describe the programmes in detail, I think it is useful to ask



Handicapped girl at work making shoes.

ourselves what are the reasons for the high level of youth unemployment we are facing, and can expect at least for the next few years? The MSC state that:

- There has been a major world economic recession, and this country, along with others, has too many people for too few jobs.
- The bulge in the birthrate in the 1960's, means we now have a higher number of school leavers.
- Changes in the structure and technology of industry and commerce have resulted in many unskilled jobs disappearing; these were the jobs which, traditionally,

many less-academic young people expected to get.

- In a situation where there are more people than jobs, the lack of skills and experience of young people leaving school puts them at a disadvantage.

The MSC's declared aim is that: "No Easter or summer school-leaver should still be unemployed at the following Easter without having had the offer of suitable training or employment."

In order to achieve this training programmes will be developed to meet the needs of young people— from 16-18 years, under the Youth Opportunities Programme (YOP); from 19-25 years, under the Special Temporary Employment Programme (STEP).

The Youth Opportunities Programme (YOP), is intended to provide an introduction to the world of work; an opportunity to try out a range of different kinds of jobs; further education and advice on how to look for a job.

This will be done through schemes in local industry and commerce, local authorities and sometimes

Grants help with trial periods

THE JOB Introduction Scheme (JIS) offers grants of £30 per week, for a six week trial period, to employers who engage a disabled person who is unemployed. Extended trial periods of up to thirteen weeks will be granted exceptionally, when disabled people need longer to demonstrate their ability to do the job.

First introduced for one year in July 1977, the scheme has had encouraging results and has been extended until January 1980. It is operated in cases where an employer's reservations about the suitability of a disabled person might be removed by a trial period.

If you think JIS could help you—contact your Disablement Resettlement Officer at your nearest Job Centre or your local Careers Officer.

voluntary organisations. These schemes will involve courses at local colleges and work experience in local factories or offices, or a specially set up training workshop. Trainees receive an allowance of £19.50 a week during this period.

The Special Temporary Employment Programme for 19-24 year olds, provides an opportunity for young people who have been unemployed for six months or more, to acquire additional basic skills, confidence and a sense of purpose, through work on a short-term project of benefit to the community.

The programmes themselves are not pre-planned and packaged by the MSC. They should be organised locally by a combination of sponsors—which could include organisation's such as ASBAH Local Associations—who then apply to the Area Manpower Services Commission Board to finance the scheme. Each Area Board has a budget, although the amount varies from area to area. Guides for Sponsors are available from the MSC, explaining how to set up such a scheme.

Slow take-up

Applications for finance for programmes have been accepted by Area Boards since April, 1978, but up-take has been very slow. If the MSC's aim is to be achieved, more sponsors must come forward.

It would be very helpful if ASBAH Local Association, would ask the local Department of Employment, Job Centre or Area MSC Board about schemes in their locality and if there are none, ask Local Authorities and Employers and Trade Union organisations what plans they are making to contribute to the programme.

Guides for sponsors and leaflets explaining the schemes in detail are available from: The Manpower Services Commission, Selkirk Hse, 166 High Holborn, London WC1V 6PF.

If you cannot find the address of your Local Area Manpower Services Board, please get in touch with Beverley Holland, ASBAH Information Officer, who has a list.

BARBARA NEWMAN
Education, Training and
Employment Officer

IN 1977, the Minister for the Disabled set up the Silver Jubilee Committee on Improving Access for Disabled People. It has just presented its report to the Minister. Has it achieved anything and where do we go now?

Evidence poured into the Committee about how widespread and serious access problems are. Things may be improving but disabled people still often find it difficult to go where they want to or to get into the building when they get there.

Planners, architects and builders in the past rarely thought about the disabled and even today mistakes are still being made. One new health centre, for example, had a very nice toilet for the disabled—except that when you got in in your wheelchair you couldn't shut the door!

People's attitudes can still be a problem too. The chairman of a large entertainment company justified turning people in wheelchairs away from his dance halls on the grounds that "hardly any of them want to go dancing"!

In the face of this evidence, the Committee concentrated on organising a public campaign. The campaign included an award scheme for areas which had made real improvements over the year, a competition for schoolchildren to present projects about access problems of the disabled, a specially commissioned film for architects and a survey of the access situation in cinemas and theatres up and down the country. All this led up to a national Access Week in June.

The campaign was a mixed success. It did focus a lot of attention on the problem and make many people stop and think—maybe for the first time. It did lead to some changes for the better. In Kirklees, for example, where the Authority was going to ignore Access Week, one of our own members made it sit up and take notice. As a result, a group has now been set up in that area, including representatives of the handicapped, to look at the local access problem. In many areas, though, nothing happened. Was your area one of these?

The problem is so enormous and so many people are still ignorant or apathetic that the campaign obviously needs to go on. The Minister has now agreed to appoint a permanent Access Committee.

ACCESS: WHICH WAY NOW?

by TIM ROBINSON, a member of the Silver Jubilee Committee

This will be responsible for making sure things don't stagnate again and for looking at suggestions for improvements.

The present committee has suggested that there should be regular Access Weeks every year and that more needs to be done to educate schoolchildren of all ages about the problem. It has also suggested that the new committee looks carefully at whether we need laws to outlaw discrimination against the handicapped. Persuasion may not be enough.

Other action may also be needed by Government and local authorities. Fire and safety regulations, for example, are often used as a reason for excluding or limiting the numbers of disabled people who can go into a building. Consequently the Committee has asked the Home Office to look at the situation and see if it can be changed.

Again, in theory, all new public buildings should be accessible to the handicapped "as far as is practicable and reasonable". Unfortunately many architects and planners are still ignorant about the problems and even if they are pointed out to developers, they can easily ignore any advice they are given. So the Committee has suggested there should be an Access Officer in every local authority. In addition there should be a committee, including representatives of all the main disability groups, which would advise the Planning Department.

Finally, the Department of the Environment has agreed to look seriously at the idea of giving the law some teeth so that developers cannot so easily ignore the requirements of the disabled.

In the end though it's up to you to make sure things keep moving. Don't just sit back and leave it to someone else.

YOUR RIGHTS

THE COST of living for the disabled is often more expensive than that for the able bodied. Yet their income is invariably lower.

Starting from that simple truth the rights and benefits available to disabled people are of crucial importance. But, sadly it is all too easy for the prospective claimant to be frightened off by the complexity of trying to secure an essential benefit.

And it is that problem which makes the "Disability Rights Handbook for 1979" such an important publication. It has been published by The Disability Alliance and it does a great deal to penetrate the general fog which invariably accompanies rights legislation. It is essential reading for the disabled and people concerned with their welfare.

LINK is grateful to the Alliance for permission to extract this sample from what is, in fact, a goldmine of information. And the next issue of LINK will follow-up with a second part which will deal with Supplementary Benefits and other grants and allowances.

However LINK strongly recommends the full text. It is available from The Disability Alliance, 5 Netherhall Gardens, London NW3. It costs 70p (by post 85p). And there is a half-rate offer for orders of 20 or more from voluntary organisations concerned with disabled people.



FIRST, some important names, how to reach them, and a word of caution.

General information can be obtained from your local social security office—you will find it in the telephone book under Health and Social Security, Department of; and from advice centres. If you have some idea of what you are after, leaflets will also be available from the post office.

You should also be aware of your local social services department. It provides local personal and welfare services and can be found in the telephone book under the name of your local authority . . . for example, Essex County Council; and then under the heading Social

Services Department you will find a telephone number for your area office.

The caution relates to the short guide which follows. It is intended only to point the way. It is not comprehensive. Only by having your individual circumstances assessed will you discover if you are entitled to a benefit. It's worth asking. In your locality you may have a Welfare Rights Officer who will be found through the Citizens Advice Bureau, the Council of Voluntary Service, or the local authority Social Service Departments. It will also be possible for you to obtain an interview with an officer of the Department of Health and Social Security if you have doubts regarding statutory benefits.

Invalidity Benefit

What is it?

Invalidity benefit is a weekly payment for people who have been receiving sickness benefit for at least 28 weeks, and replaces sickness benefit. It has two parts—a pension and an allowance which is paid to people who become unable to work more than five years before pension age. It is available only to people who have paid enough national insurance contributions.

How do you qualify?

You must have been unable to work for 28 weeks. If during that time you have received sickness benefit you will be entitled to have it replaced by Invalidity Benefit. You will continue to need a doctor's statement, and men must be under 60 and women under 55, on the first day they become unfit for work.

How much do you get?

Each week you will receive ● £19.50 for yourself, ● £11.70 for an adult dependant, ● £5.35 for each child in addition to the £4 child benefit starting in April. The allowance ranges from £4.15 to £1.30 depending on age.

Are there any restrictions?

You cannot receive Invalidity Benefit while receiving any other national insurance or industrial injury benefit. If you are entitled to more than one you will receive the higher. Attendance Allowance, Mobility Allowance, Maternity Grant or Disablements Pension are not affected. Limited earnings from work done because the doctor thinks it will be good for you do not count against the allowance. A wife may earn up to £45 per week before your benefit is affected.

How do you claim?

The key is the national insurance doctor's statement, formerly a medical certificate. Fill it in and send it in as soon as possible.

Non-contributory Invalidity Pension

What is it?

NCIP is a benefit available to those people who have not paid sufficient national insurance contributions to qualify for the Invalidity Benefit.

How do you qualify?

The requirements are similar to those for the Invalidity Benefit, but men must be under 65 and women under 60 when they start receiving the benefit; there are residential qualifications, and married woman or a woman being supported by a man will not qualify (see HNCIP below).

How much do you get?

Each week you will receive ● £11.70 for yourself, ● £7.05 for your wife, ● £5.35 for each child in addition to the £4 child benefit, starting in April.

Are there any restrictions?

You are only entitled to receive up to £11.70 in national insurance benefits. Attendance and Mobility Allowances do not count against payment. If you are receiving a supplementary benefit you can apply for NCIP as of right but it is likely that the supplementary benefit will be reduced by £11.70. However there is an advantage. NCIP is not means tested and you will be credited with national insurance contributions. You can earn a limited amount from work approved by the doctor and a wife can earn up to £45 before it affects the payment.

How do you claim?

Get leaflet NI 210 from a social security office. Fill in the attached form and return it to the office.

If you are under 18

It is advisable to claim supplementary benefit at 16, and at 18 claim NCIP as well. This will be offset against your supplementary benefit but this is the best formula.

Non-contributory Invalidity Pensions for Married Women (Housewives)

What is it?

The Housewives NCIP is available to married women and common law wives who need not have paid national insurance contributions. It is not means tested and it is not taxed.

How do you qualify?

You must be receiving £11.70 or more in support from your husband or the man you live with. (If you do not receive this much you should claim under the NCIP arrangements—see above). Other requirements are similar to those for NCIP but additionally, *and very importantly*, you must be incapable of doing your normal household duties and have been so for 28 weeks.

How much do you get?

The basic rate is £11.70 per week.

Are there any restrictions?

You cannot receive HNCIP if you get £11.70 or more in national insurance benefits. Attendance and Mobility Allowances do not count. If you receive less than £11.70 from other benefits you can have the balance from HNCIP. The advantage of HNCIP is that it is legally yours and brings with it Class I national insurance qualifications. You can earn a limited amount from work approved by the doctor.

How do you claim?

Get leaflet NI 214 from a social security office, fill in the claim form and return it to the office.



Mobility Allowance

What is it?

The Mobility Allowance is a non-means tested, cash payment designed to help the severely disabled enjoy greater outdoor mobility. How you spend it is up to you, but it is taxable.

How do you qualify?

The scheme will apply to people between the ages of five and 65 but it is being phased in and so far people between five and 58 may apply. You must be unable, or virtually unable, to walk and be likely to remain that way for 12 months.

How much is it worth?

You will receive £10 per week and be exempt from Vehicle Excise Duty.

Are there any restrictions?

By and large Mobility Allowance stands on its own and will not be affected by, or itself affect, other earnings and benefits. But recipients cannot continue to receive a Private Car Allowance or retain the use of an NHS trike, which is being phased out.

How do you claim?

Get leaflet NI 211 from a social security office, fill in the form and send it to the appropriate address.

Invalid Care Allowance

What is it?

It is a payment for people who cannot work because they have to stay at home to care for a severely disabled relative. Married women do not normally qualify, but a single person, caring for a handicapped child, could. The allowance is not means tested and not linked to national insurance contributions, but it is taxable. Those receiving it are credited with Class I National Insurance contribution which preserves pension rights.

How do you qualify?

You must spend at least 35 hours each week caring for a severely disabled person who is a relative by birth or marriage; women must be between 16 and 60 and men 16 and 65; you must not be working (earning over £6 weekly), or on a full-time course.

How much is the allowance?

Each week you receive ● £11.70 for yourself, ● £7.05 for your wife/housekeeper, ● £5.35 for each child in addition to the £4 child benefit starting in April.

Are there any restrictions?

You cannot receive Invalid Care Allowance if you are receiving the same amount or more from a basic national insurance benefit. Mobility and Attendance Allowances do not count and payment of ICA to you does not affect the benefits of the person you are looking after. You must not earn more than £6 a week after expenses and if your wife or housekeeper earns, or has benefits of more than £7.05, you will not receive ICA for her.

How do you claim?

Get leaflet NI 212 (Invalid Care Allowance) from your social security office. Ask for a free stamped addressed envelope, fill in the form and return it to Controller, ICA Unit, Central Office, Norcross, Blackpool, FY5 3TA.

Attendance Allowance

What is it?

The Attendance Allowance is a tax-free payment for adults and children, over the age of two, who are severely disabled and have needed a lot of attention for a period of six months. It is designed to help them secure the attention they need.

How do you qualify?

Disabled people who require frequent, prolonged, or continual attention by day, or by day and night, qualify.

How much do you get?

There are two rates. If you require attention day *and* night, the rate is £15.60; if it is day *or* night, the rate is £10.40.

Are there any restrictions?

Attendance Allowance is not affected by other earnings or benefits.

How do you claim?

Get leaflet NI 205 from your local social security office. Fill in the claim form and return it to the office.



**More about
your rights
in the
next issue
of LINK**

Independence Weeks-1979

INDEPENDENCE Training Weeks for young people with spina bifida and hydrocephalus.

Dates for 1979

March 11-18: Five Oaks, Ilkley, Yorks. 16+ age group.

April 28-May 5: Jane Hodge Holiday Home, S. Wales. 13-15 year age group.

August 20-29: New Mossford, Barkingside, Essex. 9-13 year age group.

November 10-17: Five Oaks, Ilkley. 13-16 year age group.

These dates and venues are provisional, but will be confirmed as soon as possible.

In addition to these Independence Weeks which are being run by National LIFT, I hope that there will be several weeks run by Local Associations, hospitals and/or schools in conjunction with national staff.

For more details about any of these Independence Weeks please get in touch with me at National ASBAH office.

Jan Tomlinson

The Importance of Independence

by Niamh Murray—Social Worker

IT IS surely the hope of most parents of spina bifida children that their youngsters will become independent people who are capable of giving something to and gaining from the environment in which they find themselves.

Independence is a big word and encompasses many aspects of daily life. It is not necessarily confined to a person being able to look after himself entirely and needing no help from anyone else. Someone who can't move a muscle may achieve his own level of independence. Independence, I feel, is largely an attitude of mind—it is this attitude that I would encourage parents to foster in their children from the time they are tiny tots.

A child who is clinging and over-protected will grow into a clinging dependent teenager and while parents may find it easy enough to comply with the whims of

a toddler, they find it infinitely more difficult to be tied to a youngster of seventeen or eighteen, particularly when parents themselves are getting older and perhaps less able than they were to be lifting and carrying all the time.

Difficult and perhaps callous as it sounds, parents should start to teach their children to be independent almost from the time that they first get them home from hospital. They should accept the fact that they are not the only ones who can look after the child and get the services of a baby sitter to enable them to get out occasionally. A spina bifida child will not break if left with a relative for a time while parents get a chance to go out together or perhaps take a much needed holiday.

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Continued from page 11

I have occasionally seen marriages suffer when a mother becomes so involved with her child that she refuses to leave it with anyone and, consequently, her husband and other children begin to feel neglected and left out. Another point to remember is that, unfortunately, many spina bifida children are hospitalised fairly frequently when they are young and the child who has learnt not to be dependent on one person only will suffer far less when the time of separation arrives.

As the child gets older, he must learn that he is part of a family and cannot be the centre of attention at all times. He should not always come first. He should learn to take his turn and should realise that all of his demands cannot be instantly met. Other children in the family also have problems and, while these are not so visible as those of a spina bifida child, they are none the less as real and as important to the child concerned. Children can certainly gain a great deal from having a handicapped brother or sister but this should not mean that they should be penalised in any way because they can walk and their spina bifida sibling can't.

As soon as the spina bifida child is able, he should be encouraged to do as much as possible for himself; i.e. dressing himself; emptying a urinary device; looking after personal hygiene etc. Dressing may often take up to an hour, it is quite understandable for a mother who has to get other children out to school that, rather than cause further delay, she will finish the job herself. However, where possible, she should persist in letting her child look after himself, even if only at weekends, as it is very difficult to train a fifteen year old to dress himself when he has had it done for him all his life. Similarly, the importance of hygiene must be stressed from a very early age.

Better equipped

Adequate socialisation for spina bifida children is also very important from an early age. They should be allowed to mix with other children in the area and learn to take the same knocks as all kids. Admittedly able-bodied children may be cruel and ask such awkward questions as "why can't he walk" or "what happened to your legs", but it is better for spina bifida children to come up against this and learn to adjust to it, as children will, at an early age. They are then better equipped to coping with possible rejection from able-bodied people when they are older.

To many parents, this type of attitude may seem very coldhearted, but one must accept the fact that you can't spare your child from being hurt, much as you would like to. Spina bifida children have so much more to be hurt about than able bodied children but they also have normal resilience and are better able to learn from a young age to develop a thick skin. It is harder for parents to stand by and watch their child being left out of a game or falling in love, as most youngsters do, and being rejected. You will however, do your child a far greater service if you don't rush in to protect him, but let him fight his own battles. He is then more likely to grow into a stable adult,

Reprinted from the Irish Association's magazine AID.

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REMAP meets individual needs

MANY disabled people have very individual problems, and there may be nothing available on the open market to meet your particular needs. Aids and equipment need not necessarily be sophisticated or expensive—a simple adaptation to existing equipment may be the answer, but you may need an aid designed especially for you.

A voluntary organisation called REMAP recruits engineers, doctors, craftsmen, and therapists who all work together in local groups to provide just this kind of “one off” solution for individual disabled people. The photos illustrate the kinds of problem they can tackle.

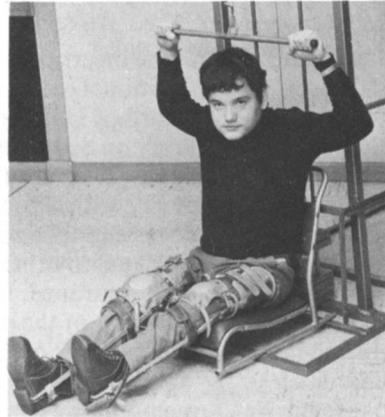
If you would like more information, or you have a problem you think REMAP might solve, please contact me at National office. If you have relevant skills to contribute and would like to work for a local REMAP group, please contact the organiser, Mr. N. Brearley, Room 277D, Thames House North, Millbank, London SW1P 4QG.



Angela Hampton, from Aldershot, uses an electric sewing machine adaptation, designed by a REMAP group.



Lorraine Hunt, from Coventry, has had extra stabilisers added to her pram to prevent it from tipping.



Gary Spencer, demonstrates a weight-lifting frame, to develop arm and shoulder muscles. It was made by a REMAP group for Mere Oaks School, Wigan.

Making play an adventure

ALL CHILDREN need a place to play, freedom to make a noise, express themselves, experiment and investigate, and handicapped children need this freedom even more than others. Surroundings which stimulate their imagination and challenge them to face and overcome risks will help to build up self-confidence and independence.

HAPA—the Handicapped Adventure Playground Association—was formed to provide these opportunities. Their latest publication, *Adventure Playgrounds for Handicapped Children*, describes the work of the four London playgrounds, and is an extremely valuable resource book for anyone starting a playground, or thinking about making a school playground, or even a back garden, a little more adventurous!

Available from: H.A.P.A., Fulham Palace, Bishops Avenue, London, SW6 6EA. Price £1.00, plus 20p postage and packing.

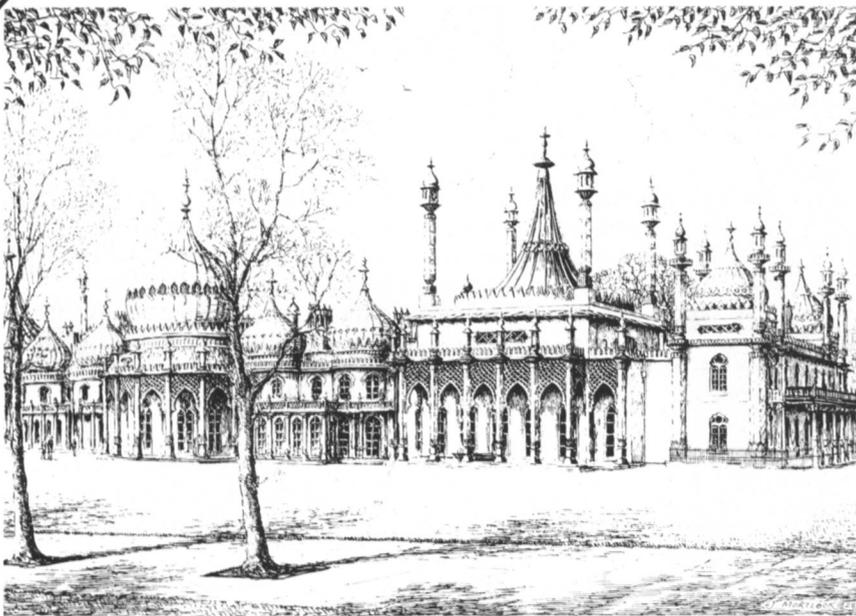
Homemade successes?

The Disabled Living Foundation are expanding their service to include information about “one off” and “do-it-yourself” ideas. If you have devised any successful aids or adaptations please let me have details (preferably including a drawing or photo!) so that I can pass these ideas on.

Stayflex

IF YOU tried the Stayflex material advertised in previous issues of LINK, please let me have your comments—good and bad!—so that we can decide whether or not to continue to supply the material.

JILL VERNON.



THE ROYAL PAVILION. BRIGHTON. SUSSEX

Here's a dinner to write home about

ALL THE glamour and excitement befitting the splendour of The Banqueting Room of the Royal Pavilion, Brighton will be provided on the evening of Thursday, March 29, at an event which is believed to be the first of its kind held in this exotic Prince Regent's Palace.

A Gala Literary Dinner to raise funds for ASBAH is being organised by Barry J. Mishin in collaboration with Hatchards of Piccadilly, London who also have a department in Hannington's of Brighton.

Distinguished

The Guest Speaker is Mr. David Attenborough whose new series, "Life on Earth", on BBC2 Television, is being widely acclaimed. In addition, invitations are being extended to 16 distinguished writers to "Host" the individual tables and at the time of writing, acceptances have been received from Roald Dahl, Hammond Innes, Miss Denise Robins, Miss Patricia Neal (American Oscar winner) and Miss Claire Lorrimer.

Their Worships the Mayor and Mayoress of Brighton will also be in attendance amongst numerous other personalities.

The occasion, hopefully the first of many, is being "stage managed"

in the theatrical sense, with additional exterior spot lighting, a Guard of Honour, a fifty-piece Brighton Scout Band at the entrance, a fanfare to announce the entry of celebrities, footmen to open car doors and take tickets and special carriages to bring the VIP guests to the entrance. It is hoped that at least part of the event will be televised by Southern Television.

All in all it should prove to be a memorable evening—as well as raising much needed funds for ASBAH. The tickets, priced at £15.00 per head, are going to be in short supply due to the numbers being restricted to 160 and demand is already appearing heavy.

ASBAH's first literary dinner promises to be an event worth looking forward to.

JUDY KAY

International round-up for riders

THE third International Conference on Riding for the Disabled will take place at Warwick University and at the National Equestrian Centre in Kenilworth, Warwickshire from 24-27 September, 1979.

WAKE UP, LINK readers . . . Spring is here. Chase away the Winter blues and please write a letter to LINK. A good Letters Page is a vital part of a lively magazine, and during the past few months many LINK readers seem to have hibernated. If you have any interesting views or comments, please put pen to paper and write to LINK. It is the only way we know whether or not LINK is being read, and you never know where it may lead. See Mrs. Phillips' letter below.

I look forward to hearing from you.

Susan Gearing
Editor

Others feel the same

IN THE July/August issue of LINK, I was overjoyed when I saw my letter printed, under the heading "Hydrocephalus, Why always second place?" The response to my letter was overwhelming. Having been approached by a large number of people who had read my letter, I was happy to know that so many people agreed.

In fact, a story about my son Derren and hydrocephalus, was to be printed in three local papers. Unfortunately, due to an editorial dispute, this was not possible. Nevertheless, I would like to thank LINK for printing my letter, and a special thank you to Mrs. Margaret Stimpson of Charlton, London and Mrs. Ruth Humber of St. Clements, Jersey, who wrote to offer their opinions. It is nice to hear other parents' views.

Derren, who has appeared on Thames Television on four occasions since last August, and has also come under one of five categories in '1979 Year of the Child', is happy and progressing well.

It has been very exciting for me. I'm feeling very proud that all this could happen.

I sincerely hope that there is a bright, promising future for all the children who are sadly afflicted with spina bifida and/or hydrocephalus, and their parents, too. We can give plenty of love, and that in itself, goes a long way. My thanks to everyone.

MRS. GILLIAN PHILLIPS
(single parent)
Wallington, Surrey.

CLASSIFIED 'ADS'

Adverts for next LINK must be in by April 1.
 The address is: LINK Advertising, ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ.
 Rate: £1.00 for up to 25 words. £2.00 for 25-40 words, £3.00 for 40-60 words. Please send remittance with your advert. You may like to pay for a whole year's advertising in one go.

HOLIDAY ACCOMMODATION

CAMBER SANDS: Well-equipped and adapted chalet (sleeps 6). Bookings taken from January by Mrs J. Wilson, 23 Sunnysdale Gardens, London NW7. Tel: 01-959 2962.

SELSEY, Sussex: Well furnished mobile home with 3 bedrooms. Sleeps 6. Fully equipped kitchen and bathroom. Large lounge with dining area. Ramp for wheelchair. Please send s.a.e. for details to: Mrs B. Armour, 17 Hernbrook Drive, Horsham, Sussex. Horsham 3980.

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

PRESTATYN: 6 berth caravan, accessible all amenities. Special reduced rates out of season. Details: Mrs E. Taplin, Colonial House, 63 Corporation Street, Manchester M4 3DT.

MABLETHORPE, Lincs: Two well-equipped chalets, self-contained, 6-berths, at Mablethorpe Chalet Park, Links Road, Mablethorpe. Details: Mr. B. Guest, 57 Bloxwich Lane, Walsall.

MILLENDREATH, Cornwall: Well-equipped chalet, sleeps six. Easy access. Details (s.a.e. please): Mr. C. Matthews, 11 Kingsbere Avenue, Ensbury Park, Bournemouth, BH10 4DL.

WESTGATE ON SEA: Semi-detached holiday bungalow, sleeps 6/8. Bath hoist, garden, 10 mins walk sandy beaches. Details: Jean Jones 01-467 8148. Greenwich ASBAH.

BASHLEY PARK, New Forest: 2 bedroomed, well-equipped chalet. Many amenities on sight. Ring evenings only: Bob Absolom, Portsmouth 68193.

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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. S.a.e. please.

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THE DISTRICT Advertising Company of EMI Elstree Studios, Shenley Rd, Borehamwood, Herts. WD6 1JG, offer a special service to charities. They produce telephone, address and notebooks free of charge, for fetes, bazaars and other events; fund-raising charts, with pockets for donations, which also help recruit membership and promote your cause, and are displayed in public houses, restaurants, on factory noticeboards and other prominent places; programmes for fetes, donkey derbys, bazaars and football matches etc. Calendars and Diaries can also be obtained, all free of charge. For further information contact Mr J. A. Alter, at the above address or tel: 01-953 1600 ext. 171.

FOR SALE

Leisure Wear: White cotton Tee Shirts with green Family symbol and words 'Support Spina Bifida' £1.60 each size 22"-30", £1.85 each small, medium, large. Also quality Sweat Shirts with reverse colours in all sizes including extra large adults. All at £4.50 each plus postage. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks. For Bucks/East Berks ASBAH.

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
<i>Sex and Spina Bifida</i> by Bill Stewart	£1

(75p to LIFT members).

Information leaflets 100 for £1.30
 All available from ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 9p per booklet.

Scottish Spina Bifida Association Booklets

Growing Up with Spina Bifida,
by O. R. Nettles, MCSP, ONC... .. 30p
 Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

FUND RAISING AND PUBLICITY MATERIAL

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All available from Appeals Dept.—postage extra.

The Appeals Dept. carries a range of fund-raising items, i.e. pens, balloons, calendars, tabards, car stickers. Send for list and order form.

Flag Day equipment can be obtained direct from: Angal, 48a Holmbush Rd, London SW15 3LE (01-788 5464).

Local Association changes

THE following changes of Honorary Secretaries have taken place since the last LINK. A full list of Associations will appear in the next issue on the back page.

DERBY

Mrs. F. Ward,
17 Colwyn Avenue,
Littleover,
Derby.
Tel: Derby (0332) 23734.

SHROPSHIRE

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**THE ROYAL BATHS ASSEMBLY ROOMS
HARROGATE YORKSHIRE
17th, 18th, 19th MAY 1979**

Manufacturers of aids and associations for the disabled will be displaying their latest equipment and services for the handicapped, which includes wheelchairs, stairlifts, hoists, kitchen, bathroom, toilet aids, and electronic teaching devices.

FREE ADMISSION TO THE EXHIBITION

The exhibition will be of special interest to the disabled community and to persons concerned with the welfare of the handicapped.

Conference details:

Assistant Secretary

The College of Occupational Therapists,

20 Rede Place, Bayswater, London W2 4TU Telephone: 01-229 9738/9

Exhibition details and tickets:

Naidex Conventions Limited,

Temple House, 36 High Street, Sevenoaks, Kent TN13 1JG. Telephone: 0732 59533/4



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