

LINK



Association for Spina Bifida and Hydrocephalus/ASBAH 20p

July/August 85



**DIG
celebrates**

**Lost babies
group**

Letters

**Living
Options**

**Treloar
College**

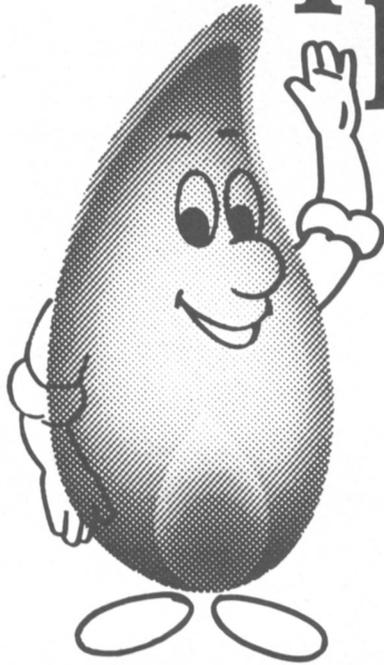
**Independence
education**

Jubilee Trust

Cover photo:
Britain's first
spina bifida
grandmother
SEE PAGE 7

INSIDE:
*Guidelines on
fund-raising*

“Help yourself to the help you need.”



British Gas offers a wide range of help to those who need it most — elderly and disabled people.

If you have a disability — or have friends or relatives in need of help — here are some of the ways in which we can make life easier for you.

COOKING

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

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

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

GAS FIRES

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

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

CENTRAL HEATING

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

PAYING FOR GAS

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

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

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

HOW TO HELP YOURSELF

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

MORE HELP

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

BRITISH GAS

Link⁹⁹

Association for Spina Bifida and Hydrocephalus/ASBAH

Correspondence to ASBAH at the National Office:

22 Upper Woburn Place,
London WC1H 0EP
Registered Charity No. 249338
Tel: 01-388 1382/5

Patron:
HRH The Duchess of Gloucester

Chairman: Mr D M Bryant

Hon Treasurer:
Mr A K Stewart-Roberts

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

Executive Director:
Miss M P Gilbertson,
MCSP, FBIM

Finance Officer:
Mr Derek Knightbridge, FCCA

Appeals Director:
Miss Judy Kay, MIPR

Services Director:
Mrs B Newman

Administrator:
Paul Dobson, BA (Hons)

Public Relations Manager:
Mrs Madeleine Legg, MIPR

Information Officer:
Miss B Holland, BA, MIPR

Disabled Living Advisers:
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Miss Mary Small, Dip OT, SROT
Miss Clare Michelmores,
RGN, HV

Fieldwork Co-ordinator:
Mrs T Cole, MICA

Accommodation & Development Officer:
Ms Siobhan Rowe, BA, Dip HA

Project Leader at Five Oaks, Ilkley, Yorks:
(Tel: 0943 609468):
Mr Jim Stanton

Link Editor:
Mrs Susan Gearing

LIFT (Young ASBAH) Organisers:
Paul Cooper, BA
Ann Monaghan

Attenborough Committee seeks to open up the Arts

WIDE-RANGING recommendations to involve more disabled people in the arts are contained in a major report *Arts and Disabled People*, which was published at the end of May.

The report is published for the Committee of Inquiry into the Arts and Disabled People under the chairmanship of Sir Richard Attenborough.

It says disabled people are too often excluded from the arts, either as artists or audience.

Recommendations for action are made to the Departments of Environment, Education and Science, Transport, the Home Office, health and hospital Authorities, Manpower Services Commission, Minister for the Arts, the Crafts Council, the Arts Council, local authorities, libraries and national disability organisations. The recommendations apply also to the respective Northern Ireland, Scottish and Welsh departments.

In his preface to the 176-page report Sir Richard Attenborough says: "Our report is designed to chart the way. It lies within the power of our generation to transform the lives of disabled people and to enrich the world of art itself by their greater involvement. Failure to act diminishes us all".

The report says that disabled people are not given sufficient attention by arts and heritage bodies, including funding agencies. Venues often fail to take the trouble to provide them with adequate information. And arts employers

frequently fail to fulfill their obligations under the employment quota.

Far more people are affected by the lack of provision than is usually appreciated. The committee took as a working assumption that one in ten of the population has some kind of disability and that this affects one in four families.

The report uses the term 'arts' to include crafts. Among the activities considered are: dance, drama, film, puppetry, music, mime, storytelling, drawing, painting, sculpture, pottery, photography and literature in addition to museum and library services. Both professional and amateur arts are covered.

Changes called for range from ways to improve access for disabled people to all arts buildings, increased Arts Council funding of specific disabled people's needs, to the importance of all new hospitals providing facilities for arts activities by disabled people.

The report states: "The arts should never be regarded as open only to a privileged elite. The arts are for everyone. To some degree, it is within everyone's capacity to reinterpret their own experience and to share the experience of others by involvement in the world of art.

"Over the ages, the arts have been the field for and have prompted some of the finest achievements of the human spirit".

The Committee, made up of members with experience of a wide range of arts activities, was appointed by the Carnegie UK Trust in 1982.

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"With reference to Mr Griffith's letter in LINK . . ."

DAVID Griffith's piece, reprinted in the May/June edition of LINK, makes some valid points but unfortunately they are lost in a welter of inaccurate observations. With specific regard to his comment about Banstead Place — that "despite being much vaunted, we sport nary a limping individual where it matters", David Griffiths really is (a) tilting at the wrong windmill, (b) inaccurate and (c) gratuitously offensive.

Employment policy at Banstead Place is to offer equal opportunities to all applicants, and we currently employ members of staff with disabilities. I am sure that David Griffiths does not need to be reminded that not all disabilities are visible ones! We also have a number of volunteers with disabilities who join in a wide range of activities.

If David Griffiths really wishes to open up professional employment opportunities for people with disabilities he would do better to discuss the issue constructively with those responsible for initial training, rather than venting his spleen on those already committed to this task. In this way he might be able to make real progress, instead of allowing himself to be dismissed as someone who sounds off without bothering to check his facts.

A. J. Kent

Principal, Banstead Place, Surrey

MRS Morigue Cornwall, Mobility Officer at Banstead Place Mobility Centre had some different points to make in a letter she sent to LINK:

I felt really saddened to see that some disabled people, hopefully only the minority, are still thinking in terms of "Them" and "Us" . . .

I think Mr Griffith's second paragraph about disabled toilets is an excellent example of the complex nature of the problem. For someone like Mr Griffith, a high toilet seat is a definite disadvantage. However, for many disabled people, a high toilet seat is essential. It depends entirely on the individual and the disability.

All of us whether able-bodied or disabled, are different and have different requirements in life. How do we design the world to suit each one of us? . . .

MANY young disabled people expect, for example, free or nominally priced holidays. What

David Griffith's outspoken "Opinion" piece in the last LINK when he exhorted disabled people to stand up for themselves has prompted some robust replies.

about young able-bodied people? They have no supporting charities to turn to:

Are free holidays compensation for being disabled? Are able-bodied people trying to make life one big long holiday for the disabled? When disabled people get into the cinema for free why is it called "positive discrimination"? Discrimination is discrimination! People are looking down on you and thinking of you as less than themselves.

How is this situation going to change? Well, as disabled people fight to become equal they have got to shed patronising, positive discrimination attitudes; "No I will not accept money for this and that. Other young people do not have it so easy".

What I am saying is that if you want equal rights with able-bodied people you have also got to perform the duties able-bodied people do. In a lot of ways, this means "paying your way".

You cannot be treated as an equal and still want to go into the cinema for free. The two do not go together. Attitudes will only change towards you if you are prepared to help the situation along. Perform your duties to other people and society as a whole, then your rights will follow.

I say this because rights and duties are inseparable. Try hard; prove yourself; do not be patronised; do not expect the easy option. People will respect you, then you will be their equal.

Paul Cooper *Lift Organiser*

I WAS rather disturbed to read David Griffiths' condemnation of Blists Hill Open Air Museum.

Mr Griffiths voiced many of these criticisms in the local newspaper several months ago without contacting the Museum first and I subsequently discussed the matter with him at some length. On the day that he visited, it is true that the

disabled lavatory was being used as a store for cleaning materials. This was an unforgivable lapse and immediate steps were taken to ensure that this would never happen again.

As for his other criticisms, the aim of Blists Hill is to recreate a typical East Shropshire community set at the end of the last century. Unlike the other sites of the Ironbridge Gorge Museum, it is not situated in a large building but on 50 acres of somewhat precipitous hillside. Nevertheless, the majority of the site is conveniently built on a level stretch at the top of the hill and all of the buildings here are accessible to wheelchair users. Ramps have been constructed where appropriate and all the staff who work in the buildings are pleased to help wheelchair users over steps at any time.

There are three main exhibits (to which Mr Griffiths refers) which are situated at the bottom of a steep hill. Because wheelchair users would have difficulty using these, we are happy to allow them access through another gate, by arrangement with reception staff. The roadways and tracks throughout Blists Hill, are of course subject to the vagaries of the English climate and will inevitably be difficult for wheelchair users from time to time. However, this has always been the case and if anything, conditions are now somewhat better than in the past.

The Ironbridge Gorge Museum Trust, which is responsible for Blists Hill is an independent charitable trust largely unsupported by public funding. It is however conscious of a considerable responsibility towards all disabled visitors and has made significant improvements to all of its sites with this in mind. All Museum staff will be helpful with special requirements and access to parts of Blists Hill which may be otherwise difficult to reach can be arranged. The telephone number is Telford (0952) 586309.

About 1,000 wheelchair users visit Blists Hill every year and complaints of any sort are extremely rare. I hope that some of those readers who have not yet seen Ironbridge will be able to visit us in the near future. If anyone experiences any problems, they will find all the staff at Blists Hill keen to help.

Michael Day
*Curator of Social History
and Manager of Blists Hill*

International Federation for Hydrocephalus and Spina Bifida

1985 International Conference 25-28 September, 1985

University of Manchester Institute of Science and Technology

THE PROGRAMME which appeared in LINK (March/April) is now nearly finalised and there are a few important changes.

Mrs Phillipa Russell of the Voluntary Council for Handicapped Children has agreed to chair the session "Making our Way/Controlling Our Destiny". This is on Thursday, September 26th.

Additionally, Dr Hugh Grenfell of Enablement Technology has agreed to come to the Conference and will probably speak on his work on

Thursday morning. He is with us for the whole Conference. Dr Grenfell has done a great deal of work on the stimulation of paralysed limbs by electrodes. He recently visited Five Oaks and there is now a set of his equipment being tested there.

We hope there will be a wide variety of items on display for delegates to see, and exhibitions will include computers, mobility items, accommodation, travel and holiday information and many other stands. If you have anything that you would

like included please do let us know as soon as possible.

The social programme is now almost complete and will include a sing-a-long pub evening (please bring any of your favourite songs) a disco, an excursion, videos and a Conference dinner. We hope that people will take advantage of the social events to mingle and to get to know each other, particularly people from other countries.

Now new buildings must be accessible

THE GOVERNMENT has made regulations which mean that from August 1985 all new offices, shops and other new buildings that are single storey and to be used by the public or for educational purposes will be accessible to disabled people.

Such premises will have to conform to the British Standard Code of Practice on Access for the Disabled to Buildings (BS5810). The regulations will also specify the minimum number of spaces for wheelchair users to be made available in new auditoria and sports stadia.

These regulations, which are subject to parliamentary approval, are far less comprehensive than many disabled people would wish, but the government has given a commitment to extending the range of the regulations.

Many disability organisations have been pressing for the basic access requirements to be included in building regulations for many years. Slightly different regulations came into force in Scotland and Northern Ireland in recent months, and a similar approach to ensuring that access is provided in new buildings has been in existence in other countries for some years.

Benefits advice by telephone

INFORMATION on social security benefits is now widely available by dialling 100 and asking for Freephone DHSS. Queries are serviced by Freephone centres around the country and in London.

British Rail offers new discounts

NEW discounts on British Rail have been introduced for disabled passengers travelling in a wheelchair. There is a standard single and return 34% discount and a standard day return, 50% discount.

Both the disabled passenger and their attendant will be entitled to the discounts as shown.

Mainline London Stations are providing yellow buggies driven by British Rail staff to transport disabled passengers to and from trains. Ask about these when making your travel arrangements.

InterChange offers help

INTERCHANGE Trust, the national community arts and resource centre based in Kentish Town, North London, has launched a new support package for self-help groups struggling against cuts in funds.

In September it is starting a series of short courses and training workshops - 'Improving Management Skills'. They will be of interest to workers in voluntary organisations, community groups and art companies.

Further information from The Advisory Services Coordinator, InterChange Trust, 15 Wilkin Street, London NW5 (Tel: 01-267 9421).

TV looks at technology

A BBC TV series is looking at the applications of micro-technology to various kinds of disability.

The devices are presented through the experiences of disabled people. The series comprises a 50-minute documentary to start it off, and five 25-minute programmes exploring the themes of mobility, access, communication, education and the process of inventing new aids.

Watch the Radio Times for transmission details. There will be an accompanying booklet and postal referral scheme for enquiries.

BARDSOFT meets special needs

BARDSOFT is a database containing information on a wide range of computer software of particular use to people with special needs. It has been launched by Newcastle-upon-Tyne Polytechnic's Handicapped Persons Research Unit (HPRU).

The data base has information on over 850 programmes, and searches can be carried out, on request, relating to specific makes of microcomputers, input switches, goals, handicaps etc. A charge of 10p per record is made to cover search, printing, postage etc.

Details: HPRV, Newcastle-upon-Tyne Polytechnic, Coach Lane Campus, N-on-T, NE7 7TW.

MSC offers money for pilot job schemes

HALF a million pounds is to be made available to voluntary organisations by the Manpower Services Commission for each of the next three years under a proposed new scheme – Pilot Employment Initiatives for Disabled People.

This was announced by the Under Secretary of State for Employment, The Hon. Alan Clark, MP at the EmployAbility Conference in Manchester organised by RADAR (The Royal Association for Disability and Rehabilitation).

The aim of the scheme is to encourage voluntary organisations to develop employment services which complement the MSC's existing services. It will provide pump-priming financial assistance.

The level of funding will be limited to 80% of the cost of the activity in the first year, 60% in the second year, and 40% in the third year and no particular disability organisation will receive more than £100,000 in any financial year.

Voluntary organisations should demonstrate they are seeking to help particular disability groups with a special need not met by MSC services, that they are responding to an identified need in a localised area, or that they plan to assist some other recognisable group of disabled people.

The activity should be specifically related to helping disabled people to obtain permanent full-time employment or sheltered work. Further detail will be available later.

Sainsbury's special trolleys

MOST Sainsbury supermarkets have shopping trolleys that can be attached to a wheelchair, and also specially strengthened trolleys to carry older children with disabilities. Do ask if they are available at your branch and perhaps make this facility known to other supermarket chains.

ASBAH studies reform proposals

ASBAH is studying the Green Paper 'The Reform of Social Security' which came out in June and several aspects give possible cause for concern, particularly in the areas of housing and additional payments and the death grant.

ASBAH will be looking at it in detail and sending in its comments. If any one has comments that they would like to pass on would they do so as soon as possible please by contacting National Office.

Microelectronic aids examined

AN International Exhibition and Symposium on Microelectronic Aids for Handicapped People – Math 85 – will be held at Derngate Centre, Northampton, October 28-30. It will cover a wide range of the latest developments in microelectronic aids for people with disabilities. The Emphasis will be on the practical application of technology.

Details: Malcolm Clough, Northants Council for the Disabled, Northampton NN1 1LG.

Telecom wants to hear from you

BRITISH Telecom would welcome views from disabled people about their payphones. They are looking for ideas for new layouts, siting of payphones etc.

Contact: Mrs. A. Smith, 114 The Boulevard, Wylde Green, Sutton Coldfield, West Midlands B73 5JG.

Swimming club register

A REGISTER of swimming clubs and organised sessions for disabled swimmers throughout Britain has been published by the National Association of Swimming Clubs for the Handicapped (NASCH), 219 Preston Drive, Brighton, Sussex BN1 6FL. Price 50p.

Public sector fails to met jobs quota

THE LATEST figures of registered disabled people employed in the public sector reveal the same picture as previous years.

No county council in England or Wales met its quota of 3% of registered disabled workers. Although Gwent managed an encouraging 2.5%, most county councils failed even to reach 1%.

Of all the district councils only 39 met the 3% quota. South Wight District Council reached 5.3% and set a fine example to Castle Morpeth, East Cambridgeshire, Hambleton, North Wiltshire, Tewkesbury and West Somerset District Councils, who share the distinction of not employing a single registered disabled person.

The London Borough Councils and the GLC also present a sorry record and only the London Borough of Newham met its quota, 3.8% of its workforce being registered as disabled people.

No regional health authority met the quota, and the highest figure of 1.5% was achieved by the West Midlands Regional Health Authority. Of almost 200 district health authorities, none met their quota and very few reached 1%.

The district health authority with the highest percentage of disabled people was North West Hertfordshire with 2.1%. Scottish Health Boards, other bodies within the National Health Service and the electricity boards were unable to achieve one 3% between them.

Quota figures do not reflect employment of *unregistered* disabled people.

Study day on spina bifida

ALL Aspects of Spina Bifida is the subject of a Study Day at the Rupert Beckett Lecture Theatre, Leeds University, Saturday September 21, 9.45 am – 4 pm. It will be chaired by Prof. R. W. Smithells and the day fee is £10 to include coffee and lunch.

Details: Miss J. Dunning, Genetic Counselling Health Visitor, A Floor, Clarendon Wing, Leeds General Infirmary, Belmont Grove, Leeds LS2 9NS.

Bursary is proving its worth

THE BURSARY set up by Prof John Lorber has already helped three young people with spina bifida and hydrocephalus. It enabled them to go on a Driving Assessment Course at Five Oaks earlier this year. (Their views on the course are printed below.)

The Bursary is open to application by any young people with spina bifida and/or hydrocephalus who need financial help to attend one of ASBAH's courses.

More donations are urgently required to boost the Bursary so that it can help many young people in the years ahead.

Here's what Jimmy (from Sussex) and Perry (Surrey) thought of the driving course:

"It was a wonderful experience which I hope to put to good use in the near future. It has given me a little more insight of actual driving and this will stand me in good stead. The friends whom I met through the course along with the instructors made for a happy time in Yorkshire. I will write again when the time comes to throw away my L plates and I am very confident of doing so one day". *Jimmy.*

"I think there should be more courses like this. We used an old airfield for most of the course and then were on the road for the rest of the week. I am going ahead with my driving test". *Perry.*

Banstead Place Mobility Centre is running Driving Assessment Courses at Five Oaks in September and a second Driving Ability Course (see page 13).

Homing in . . .

HOUSING INFORMATION.
Price 50p (including p&p).

ASBAH has produced a simple, yet informative handout on the subject of accommodation and how to set about finding suitable housing.

From: Ms Siobhan Rowe, Accommodation and Development Officer, ASBAH, 22 Upper Woburn Place, London WC1H 0EP.

LOST BABIES

THE newly formed 'Lost Babies' Support Group, made up of over 20 organisations including ASBAH, is concentrating on contacting women who had elected to have a termination of pregnancy following the detection of fetal abnormality by antenatal screening.

The group will try and establish a network of women so that they could be put in touch with each other if they wished and provide support and counselling following termination of pregnancy. This would also provide a feedback to the medical profession on the needs of women in this situation.

If anyone is interested they should contact: Clare Michelmores, Beverley Holland, or Barbara Newman at ASBAH National Office.

Banstead Mobility Centre wins AA Award

LINK READERS – particularly those who have been to Banstead Place Mobility Centre or have met ASBAH's Mobility Adviser Leonie Holgate who is based there – will be delighted to hear that the Centre has recently won a special Award from the Automobile Association.

In May, Lord Eroll, Chairman of the AA, presented the Mobility Centre at Banstead Place with the AA's Silver Award "for its foresight in establishing the only major centre in the UK providing comprehensive driving assessment facilities for the disabled".

The Award was made at a special press luncheon and two other Awards were presented to organisations concerned with other aspects of motoring.

Changes at Five Oaks

JIM STANTON, Project Leader at Five Oaks, is leaving at the end of September to pursue a social work course.

I am sure that all those who have come in contact with him at Five Oaks over the past two years, will join us in wishing him well.

Paul Cooper, LIFT organiser, will be moving north to Five Oaks to continue his work with LIFT groups in the northern area, and to take over responsibility for social and leisure activities for residents and LIFT members at Five Oaks including the special interest courses.

We shall be recruiting another LIFT organiser to work from the London office with Ann Monaghan.

Moyna Gilbertson,
Executive Director

FRONT COVER

The first spina bifida granny?

MARJORIE ILLMAN of Horley in Sussex with just three of her eight grandchildren is the subject of the front cover of this issue. It looks as though she may be Britain's first spina bifida grandmother.

Mrs. Illman wrote to LINK after seeing the story in the March LINK about Mrs. Maureen Ashton who has spina bifida and had just become a grandmother. LINK asked: "Is Mrs. Ashton Britain's first spina bifida grandmother?" Two readers wrote to say "no" . . .

Mrs. Illman writes: "Sorry Mrs. Ashton! I have two sons and a daughter – the eldest being 39. Between them they have eight children. The eldest is a girl now 15 years of age – all without back trouble".

The other letter was from Mrs. Jean Nzankowski from Cheltenham: "I am very sorry to disappoint Mrs. Maureen Ashton but I don't think she is the first spina bifida grandmother in the country. I am 60 years old and have two perfectly normal children – a boy of 37 and a girl of 32. They have two children each (one of my daughter's children does have spina bifida). My grandchildren's ages are 14, 13, 12, 11".

That makes Mrs. Illman "the champ" so far, doesn't it? Any more contenders? If so please write in and send us a photo if you can.

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Carematch – a new computer service for disabled

CAREMATCH, a computer based service to help physically disabled people to find a suitable home, was launched in London in May.

It is a major project of The Residential Care Consortium, a registered charity, formed by a group of national charities in 1981, and is grant-aided by the Greater London Council and The Department of Trade and Industry.

Carematch aims to provide a service for disabled Londoners. At present it has a database register of homes for physically disabled adults in the GLC area and 60 Cheshire Homes throughout the United Kingdom. In time it hopes to cover the whole country.

Here is how it works. The disabled individual or social worker or carer contacts Carematch which then sends a comprehensive form asking for information, always regarded as completely confidential, such as the area preferred, the type of accommodation sought, the degree and type of disability suffered, the amount of individual help in daily tasks required. This

completed form is then matched against the information on residential homes in the database and a list of possible suitable homes is then sent to the applicant.

From then on, it is up to the client to select a suitable home from the list and to make further enquiries and arrangements.

Carematch does not match clients on anything but the personal aspects of care and some preference on area and type of home. However, there is a telephone counsellor, Miss Lin Berwick. She is herself handicapped by cerebral palsy and blindness. Her own experience of the problems enable her to offer practical advice, additional information and guidance on specific problems as well as help with difficulties over completing the form.

Those seeking the Carematch Service should contact Carematch at 286 Camden Road, London N7 0BJ. Tel: 01-609 9966.

For telephone counselling contact: Miss Lin Berwick on Hornchurch (040 24) 58325, Mon to Fri 2 – 5 pm.

Link

LINK celebrates its 100th issue in September.

If you have any memories, thoughts or comments on the magazine and would like them included in this special issue please write in.

Any items, photographs, letters, are extremely welcomed – as always.

Advertisers may like to take the opportunity of helping LINK to celebrate – either in the magazine itself or in a loose insert. Contact me for details of rates, etc.

Contributions for the next issue must be with me by August 5. Artwork for advertisements need not be in until August 20, but bookings must be made early.

Mrs Sue Gearing, Editor, The Gables, Long Lane, Wrington, Avon BS18 7NE. Tel: 0934 862279.

Increasingly LINK articles are being reproduced in other magazines. We are naturally delighted, but please contact us first so that we can seek the author's permission.

Directa has ASBAH taped

TWO HUNDRED miles of sticky tape enabled one of Britain's top comedians, Russ Abbot, to present £1,000 to ASBAH on behalf of Directa UK Limited, the sponsoring company.

David Dennison of Directa UK Ltd decided to initiate a scheme "to advertise ASBAH on the company's packing tape, donating 10p to ASBAH for every roll purchased.

Receiving the cheque on ASBAH's behalf at a presentation in London in May was talented young photographer Ann Wild – herself disabled with spina bifida. Just 12 years old, Ann has already collected 13 trophies including Kodak's "Young Girl Photographer of the Year". Her portfolio of photographs has amongst them studies of the Prime Minister, Mrs Thatcher and the Opposition Leader, Neil Kinnock.



Talented young photographer Ann Wild receives a cheque for ASBAH from comedian Russ Abbot.

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Living Options

ASBAH's Accommodation and Development Officer, SIOBHAN ROWE sums up a very important report.

IF YOU'VE ever wanted a publication which neatly expresses how local services for people with physical disabilities could be improved read on . . .

In an attempt to convince health education and social service authorities to take a new look at their provision the Prince of Wales Advisory Group on Disability, assisted by many other voluntary organisations including ASBAH, has produced a short paper called "Living Options".

The publication maintains that if service providers take note and act upon the suggestions they will not necessarily incur an increase in expenditure, but they will enhance local co-operation between various services and the lives of many disabled people.

Six important principles on which provision should be based are:

Choice – on where and how to live;

Consultation – with disabled people and their organisations on the design of services;

Information – to be shared between disabled people and service planners, and better information on local facilities and provision;

Participation – in local and national communities which can only be achieved by equal opportunities in terms of housing, employment, education, industry, and leisure;

Recognition – that disabled does not mean ill, and medical models of care (ie young chronic sick units) are not always appropriate;

Autonomy – ie, freedom to make decisions about one's own life.

The report does not stop here. It continues with concrete suggestions which include the development of *Joint Care Planning Teams* involving health and social services, housing and education authorities, disabled consumers and voluntary organisations. This would improve the overall provision, establish joint

Prince of Wales group comes up with the answer

areas and priorities and could involve the combination and sharing of funds.

The report also urges authorities intending to develop residential provision to consider using the finances to provide care support services which would enable disabled people to live in their own homes.

It is also suggested that Young Disabled Units run by health authorities could be used more flexibly than just as permanent accommodation; this could include use as an assessment, rehabilitation or respite care facility.

Authorities says the report should support the development of Centres for Independent Living (CILs) throughout the country. These so far, have been started in Hampshire, Exeter and Derbyshire. CILs *controlled* and *run* by disabled people aim to develop, in their area, five basic services essential for independence and freedom of choice. These are: housing,

transport, access, poor counselling and attendant care.

The report also recommends improved continence services, house adaptations, housing provision (which in some cases could include warden support and structured care support), networks of carers to help people with disabilities to live in their community, access to transport, improved transition from paediatric and education to adult services, improved education for younger disabled people in living skills, and better training for all staff working with disabled people.

The report has been sent to all social service and health districts. It is hoped that as many as possible take up the points raised, by discussing them at their committees and councils, with disabled consumers and voluntary organisations. The authors hope all those groups interest in better provision will play a part in making sure that this happens, by asking those in control of local services for their reaction to the paper, and what they intend to do. They urge all voluntary organisations to encourage the adoption of the principles outlined and guidelines for action in their areas.

If you would like a copy of "Living Options" write to me at National Office, Enclosing 50p which includes p&p.

Newport housing scheme nearly ready

AT THE end of September ASBAH hopes the housing scheme that it is developing with Family Care Housing Association in Newport, intended for young people, will be ready for occupation.

The scheme comprises eight flats, four ground floor and four first floor. All the downstairs flats (three two bedroom and one one bedroom) are of a wheelchair standard design and include height adjustable kitchens. This will mean that in the long term they can cater for people with very different stature, and levels of disability.

The first floor, intended for able-bodied tenants, includes three one bedroom and one two

bedroom flats.

We hope that the varied size of the units will offer people the opportunity to share with friends, a partner, or to live alone.

Newport is a hilly town, but fortunately the scheme is well situated in a relatively flat area, quite close to the town centre.

The Housing Association has funded the scheme from a Housing Association Grant obtained from the Department of the Environment. ASBAH's financial contribution has been counted to paying towards the cost of the kitchen furniture.

For further information on this scheme please contact Siobhan Rowe at National.

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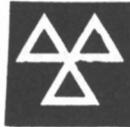
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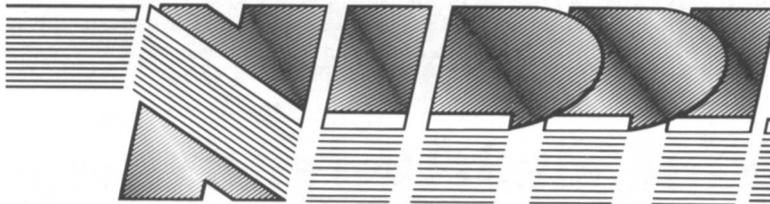
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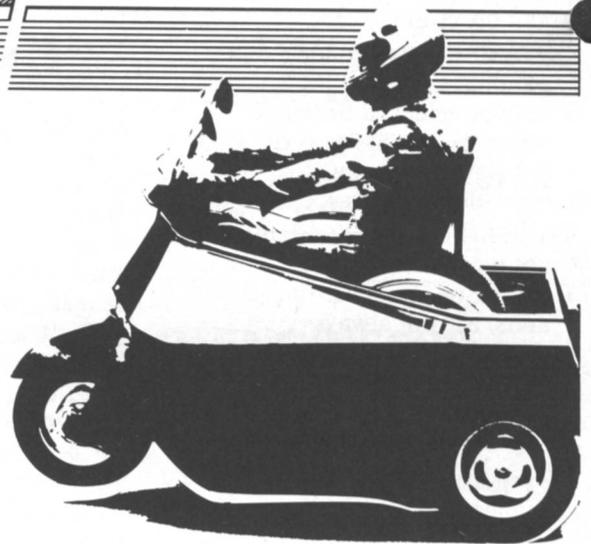
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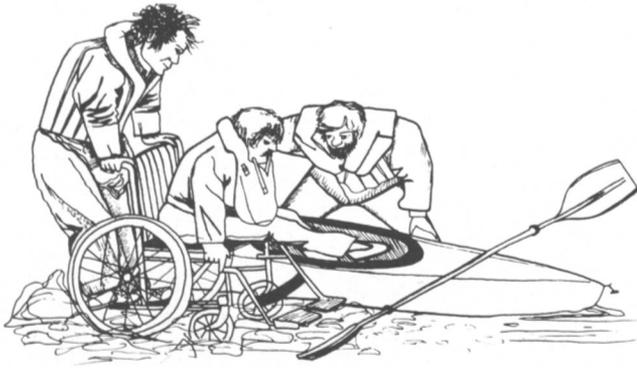
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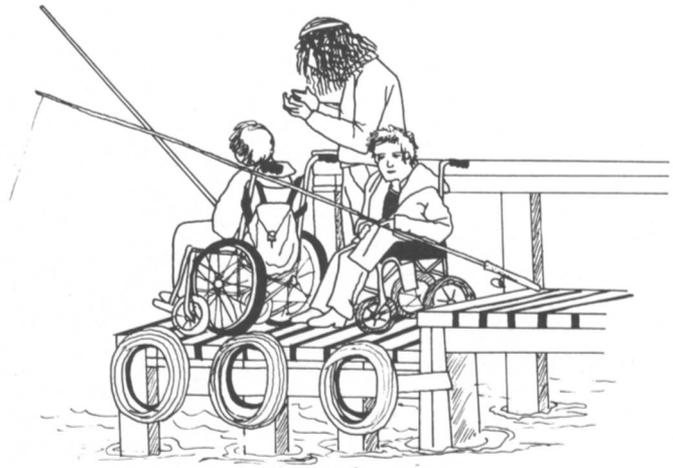
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IT'S NOT too late for a break at Five Oaks this year, where you can learn something new!

July 21-27: Outdoor Activities Week. This gives an introduction to a variety of fairly strenuous outdoor sports — canoeing, rock climbing, sailing, rambling and archery. The week will conclude with a barbeque on Friday evening. This course was filling up very quickly, but there may still be places.

August: Free choice. This month has been kept clear for you to try whatever activity you'd like to take up. You have only to ask and Five Oaks will try to bring in an expert to show you how.

Sept 6-8: Fishing weekend. If you'd like a relaxing weekend and an introduction to fishing, this is an ideal opportunity. Fishing takes place at the lagoon down by the river in Ilkley. This course is popular with local people, but anyone is welcome.

Sept 9-13: Driving Ability Assessment. More details on this page.

Oct 9-23: Holiday fortnight for young adults in residential care. This



Disc jockeying — get a taste of what it's like to be in charge at a disco!

fortnight has a varied programme of activities and visits to give young and not-so-young adults who live in residential care the chance to enjoy a relaxing and stimulating break.

Oct 26-Nov 2: Dance/Drama Week. This is an introduction to dance and drama. Who knows, it might encourage you to return to your own area and join a local dance or amateur dramatic group where

● Illustrations by Mary Small, ASBAH's Disabled Living Adviser.

Live and Learn at Five Oaks

you haven't had the courage to do so before.

Nov 4-17: Driving Ability Course. This offers an intensive 2 week training course to people who have already been assessed for driving ability and are classed as "border-line". At the end of the course the assessors will give the students a good idea of whether they are suitable to drive how long it would take and the likely cost of lessons. The cost of the two weeks is about £300. If you are interested contact Banstead Place for an initial assessment.

Disc Jockey Week (Date to be arranged). It may not always be possible to join in all the disco dancing, but you could participate fully in a different way — by being a disc jockey. This course gives you an idea of what it takes. You can learn how to use the equipment and get involved in organising a proper disco. The cost of the course is: £125 per week, and £25 per weekend. This price is all inclusive of tuition, activities, full board and 24 hour care. Anyone of 13 and over who is disabled is welcome.

If necessary ASBAH will be glad to help by suggesting possible sources of funding. Don't forget the Lorber Bursary — see page 7.

Call in for a driving check

IF YOU are interested in a full driving ability assessment then you may like to come to Five Oaks one day in September (9-13).

At the moment full driving assessments are only available at Banstead Place Mobility Centre.* However in September ASBAH is welcoming the Banstead Place team to Five Oaks.

There are still a few places available. The fee for assessment is £75 and takes one day. ASBAH can easily arrange reasonably priced accommodation at Five Oaks or nearby if you need to stay over.

ASBAH strongly advises that everyone has a full assessment before embarking on an expensive course of driving lessons, so apply quickly to Banstead Place Mobility Centre, Park Road, Banstead, Surrey SM7 3EE. Tel: Burgh Heath 51674.

*The Centre recently won a special AA award, see page 7.

DEAR LINK READERS

AS IT IS International Year of Youth I have been asked to write some words, telling you how life is in Norway for a young person with Spina Bifida.

My name is Cato Lie and I was born 23 years ago in a small town called Sandefjord. After my birth my parents were told that the possibility that I would live more than a couple of years was quite small.

An infection or hydrocephalus would be impossible to cure according to the doctors. I had both these problems, but I survived. My head suddenly stopped growing abnormally, and my bladder started acting relatively normally.

When I was about two years old several doctors tried to fix my hips, but we had to move to Holland to have it done successfully. My father was a sea-captain and was offered a job ashore for the company he had sailed for, in Rotterdam. He accepted the offer; knowing that this would improve the possibility for me to get the best possible help available at that time.

I went through a number of operations to correct the position of my hips and feet. This made me able to walk with crutches, and this situation has stabilised. So I will need these crutches for the rest of my life.

Now some words about my schooling. I went to primary school when I was six years old. It was a school just for disabled children and I enjoyed going there, because I was one of the "stronger" and most active pupils. When I think back it was a mistake for me to attend that school. The teachers didn't demand enough from me, so I wasn't prepared for the blow that was to come in the next phase of my education.

When I was 12 years old I left this school and started attending a secondary school nearby my home, where I was the only disabled among 1200 pupils. There I soon found out that things I should have known hadn't been taught me. With a lot of hard work I managed to catch up with the other pupils and I was moved to the next class.

Socially I felt that I was part of the group physically without being a member psychologically. Five years later my family moved back



In International Youth Year a 23 year old from Norway gives us a brief insight into what his life is like.

**Life has
been kind
to me**

to Norway where I finished my secondary education. These two years of my life were great, because I was looked upon as an equal member of the class.

My school work went fine, because I was used to working efficiently. My school results were good enough to make it possible for me to start at the Oslo Business School. It would provide me a four year education in economics.

The Norwegian State would pay most of the expenses.

Although the studies were hard and the exams tough, I have done quite reasonably. Especially when one takes into consideration all the other things I ended up doing in addition to my studies.

So now I'll tell you about my hobbies. When I was seven years old I started as a boy scout. I guess my parents wanted me to become as independent as possible, as soon as possible. In summer we camped in tents and made our food on open wood fires. It was a very interesting time for me, where I learned a lot. But after a couple of years I got tired of being a boy scout, so I started my "sports career".

After a few months training I participated in the Dutch Swimming Championship for Disabled, and because of my results there I joined the Dutch swimming team. I was training for the Olympics, when my coach discovered the fact that I wasn't allowed to be a member of the Dutch swimming team because I was Norwegian. That was the end of my swimming career.

While I was swimming I also started playing wheel-chair basketball. I continued with this in Norway, but there are only a few teams here so the playing level is much lower than in Holland.

In 1979 I was staying at a hospital outside Oslo. There I saw something called wheel-chair dance. It was performed by someone in a wheel-chair together with an able-bodied partner. This looked interesting to me and I decided to try it, and since then I have participated in a number of competitions together with a regular partner.

We dance whatever you can see on television in competitions where able-bodied persons participate – waltz, samba, rumba, jive and so on. The main goal is to make it look as much like "normal" dance as possible. I enjoy this hobby very much and it has brought me to a lot of different countries.

In April my partner and I were invited to go to Iceland to demonstrate some wheel-chair dancing. As far as I know, it hasn't been introduced in England yet, but I think it will be soon, because it is spreading all over Europe.

Apart from sports, I have been active in the Norwegian Spina Bifida Association.

To come to a conclusion I must say that life has been kind to me. I have got a great family that helps me when necessary and I also have a lot of good friends. I have also got a car that takes me around when I want to go somewhere.

The chances of me getting a job when I finish my education this summer are reasonable, but before I settle down I want to travel around a bit. Although it sometimes can be hard to be disabled one has to accept the fact and turn it into an advantage instead of giving up. This is a long process, and I'm still working on it. but I know I have to succeed.

Cato

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THE RIGHT of a young disabled person to education until 19 is all very well, but it does not work in practice unless the right facilities are provided

... and this is precisely where Lord Mayor Treloar College in Alton, Hampshire, comes in.

The college is investing a great deal of money, time, energy and hope for the future in plans to cope with the increasing numbers of older students needing education. The aim is to equip them with skills, not only for employment, but in view of the national unemployment situation, for an enjoyable and full life, too.

The plans centre on the building of an ambitious new vocational skills centre in the grounds of the college. It is to be called the Traill Centre after the current Lord Mayor of London, Sir Alan Traill, who has launched a national Appeal for the project. The foundation stone will be laid in November this year and it is hoped that the centre will be completed by September 1986.

The headmaster of Lord Mayor Treloar College, Mr. A. M. Macpherson, writing about the new Traill Centre, said: "Our aim is to restructure the sixth form courses in the College in order to prepare the students, as far as possible, academically, socially, in independence and finally, but perhaps most important, to develop a skill which they may use and keep with them throughout life.

"The sixth form course will last two years and the students will be expected to work normal office hours. A thorough assessment of each student's capabilities will be carried out by an inter-disciplinary team and there will be regular reviews.

"However, at present we do not have the facilities for this. Therefore, we want to set up a purpose-built assessment and therapy centre as part of the project so that physiotherapists, speech therapists and occupational therapists and others may work as a team which has the appropriate facilities for the additional requirements of this assessment.

"After assessment there will be four elements in every student's time table. The main one, which will take up half the time, will be vocation or occupation training, to

HERE LINK features the Lord Mayor Treloar College where great steps forward are being taken in the education and stimulation of the growing numbers of sixth form students.



Treloar students develop a taste for a new hobby — winemaking.

Treloar College aims to give teenagers key to brighter future

provide each student with a level of ability which will enable him or her to continue to use the skill as an occupation after leaving the College".

He gave as one example — tailoring. The headmaster normally wears a suit made by one of the sixth form students on the tailoring course. This student left to take up a job in a clothing shop, so in his case it led to outside employment. But tailoring could also be a money-making venture for someone working from home doing alterations and adjustments and

meeting individual orders.

Other skills such as those involved in horticulture or business studies may lead to an occupation in much the same way, or provide a source of satisfaction and inspiration as a hobby or leisure interest thus bringing stimulation in an otherwise housebound life.

About a quarter of each student's time in the sixth form will be spent on communication skills and personal development. Among other things these would involve the use of simple office machinery learning about money, benefits, how to conduct interviews, decision making, personal relationships and general independence training.

General studies will take up rather more than one quarter of the sixth form time and, of course, sport and games and social activities will be included.

The course will be flexible enough to accommodate the requirements of physiotherapy, occupational therapy and speech therapy.

Mr. Macpherson writes: "We have found that a number of our leavers end up watching television as their only occupation. We want to develop a course in which this new approach to our sixteen plus pupils can be carried out successfully.

"This will require a number of

specialist rooms, workshops and computer rooms. The students themselves will run an information centre where data regarding aid for handicapped people and research data from the college may be stored on computers. This would be made available to handicapped people anywhere in the country.

"The students will also run a shop where craft items, jewellery, painting done by the students, plants from the horticultural course, could be sold, but the main purpose would be to learn about the retail trade and to make contact with the public. The students will also run a resources centre. None of these facilities are at present available in the College and they would have to be provided in new buildings.

"Our aim will be to equip students to make a successful transition from school to adult life, particularly by the positive assessment and development of employable skills.

"Achievement in examinations will still be sought, but we will be more concerned with developing, to the full, all potential skills and abilities within each handicapped student and with providing everyone who completes the Traill Course with a purposeful and positive approach to his adult life. If the students leave the College feeling they are useful members of society and that they possess skills which enable them to make a contribution to that society, no matter how small the contribution is, then the system will have succeeded".

The staff at Treloar understand that the sixth formers are adults and need to be treated as such. A different approach is needed between the fifth and sixth formers. The college already has this to a certain extent, but the facilities provided in the Traill Centre will make the task that much easier.

The emphasis on flexible education for the older ones has been in progress for several years. Already 40% of sixth formers go to Alton tertiary college where they are educated to City and Guilds standards, CSE, O and A level standards.

A really concrete step in the direction of improved sixth form facilities was the opening, on October 30 last year, of Gloucester



Shared moments. Above, amusement and surprise. Below, old fashioned fun.



House, by the Duchess of Gloucester. It is a detached sixth form house set in the grounds of the Upper School of Treloar. It has been designed sympathetically with a good use of modern materials and is a real showpiece.

Here sixth formers – 26 boys in two wings, and 13 girls in one wing – enjoy reasonable independence, privacy and good facilities. There are independence flatlets where the students may take turns to live and cater for themselves – and which are proving popular meeting places in the evenings.

From September last year the total number of students at Treloar was increased to 280 (270 of these are boarders). The largest disability

group in the college is spina bifida – 89 students in all.

Treloar College came into being in 1978 when the old school founded in 1908 for boys and amalgamated with the girls school. It continues to be one of the leading colleges of its kind in the country. The range of courses available, the facilities and the lively and caring atmosphere make it an ideal educational setting for many young disabled people today.

If you would like details contact: the headmaster, Lord Mayor Treloar College, Holybourne, Alton, Hants GU34 4EN. Tel: 0420 83508.

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Steve is Britain's first disabled badminton coach

FROM playing about in the garden for fun with a racket of some description, Steve Toms has graduated to become a qualified badminton coach – the first disabled coach in Britain.

Steve, aged 34, has spina bifida and is in a wheelchair. He says he always had a hankering to teach something, but never dreamt it would be badminton.

He played the sport for fun at Coney Hill School and later at Queen Elizabeth Training College. "I used to play on Sunday evening and quite enjoyed it", he says.

Clearly Steve looked like a natural as a teacher. It wasn't long before the head of PE at Southwark Institute, Ian Jones, suggested that he might think about taking up coaching. So willing to have a go, Steve applied to the Badminton Association, and didn't let on that he was disabled until the last minute.

"I was very lucky that there was even a course being held anywhere near me", said Steve. The course in question was being run in Kent not too far from his home in South London.

When he explained that he was disabled, the Association's attitude was one of encouragement, and they offered him a place.

"They said that they had never had a disabled person on the course before".

The course, which was held over three weekends was quite taxing for Steve but enjoyable, and it culminated in an assessment for the coach's badge. Fourteen out of the 21 students on the course passed, and Steve was one of them.

He is now a paid tutor teaching on Friday nights at the Phoenix Sports and Leisure Club for the disabled in Southwark, South London. Unfortunately, because of access difficulties they can't play on the proper badminton court, but have to use the main hall on the ground floor, which is normally used by the infants as an assembly hall.

Steve lives by himself in a pleasant purpose-built flat in Rotherhithe. After going through a bad patch of 8½ years when he was unemployed, he has been working in Southwark for the past three years, first of all for Southwark Enterprise helping to find jobs for other disabled people, and then, for the last year, with Southwark Disablement Association as the Sports and Leisure worker. A post which is funded by the GLC.

A good deal of his work is involved with the problems of access, and he is also trying hard to find the many young disabled people in the area whom he feels are "hidden away" and out of touch with others of their own age.

"A lot of them like me went

The rules . . .

HOW the rules and regulations of Badminton have been altered for disabled players.

In the singles, only half the court is used; obviously foot faults do not apply for the service if the player is in a chair. The chair must not cross the service line, nor the feet or footplates.

If the player is using crutches then they become an extension of the player, and if the shuttle cock hits them it is regarded as a fault.

The service law requiring the shuttle to be hit with the head of the racquet below the waist, has been dropped, as it has proved too difficult for disabled players.

All other rules apply.

away to special school and as a result came back home knowing no-one. I'm trying to contact them and to introduce them to the various leisure and sports opportunities locally".

He would be glad to hear from any LINK readers living in the Southwark area. If anyone would like to get in touch his address is: Southwark Disablement Association, Room 48, The Aylesbury Day Centre, Boyson Road, London SE17. Tel: 01-701 7616.

"EVERYONE for music" – a one day conference is being organised in Kensington, London, by the British Society for Music Therapy, the Disabled Living Foundation and the Nordoff-Robbins Music Therapy Centre. Date: Saturday 19 October.

An overall view will be given of what can be done musically for and by people with special needs. All disabilities will be kept in mind and music in the context of education, recreation, therapy and performance will be considered.

The conference will be of interest to all concerned with disabled people either before school, at school, or as adults, and this includes families and friends. Those

A day for getting in tune

who train musicians, teachers, social workers, and therapists will also find the day of interest.

The fee is £12.50 (to include coffee and afternoon tea). (Full time students – £9.)

It is being held at the Maria Assumpta Pastoral and Educational Centre in Kensington, London.

Details and form are available from: Mrs. D. Christophers, Conference Secretary, 69 Avondale Avenue, East Barnet, Herts EN4 8NB. Tel: 01-368 8879..

Fuengirola welcomes disabled visitors

IF YOU are thinking of going to Spain for a holiday you may be interested to know that the Costa Del Sol resort of Fuengirola is encouraging disabled holiday-makers and providing some special facilities.

Holidays on Wheels is a new company providing holidays for people in wheelchairs. (The Managing Director is himself disabled.) They are promoting holidays in this resort.

Details: Mr. R. J. Cronin, Holidays on Wheels Ltd., 114 Elia Street, London N1 8DF.

THIS IS the first of a short series of articles for LINK by John Costello who lives near Nottingham. He is the parent of a boy with spina bifida and hydrocephalus and also a teacher. Here he looks at the ways — outside school — in which parents can encourage a situation which will help their children to become as independent as possible in mind and body.

PARENTS of children with spina bifida, and indeed the children themselves, often have strong views about education. For some children the advantages of being in a "normal" school are obvious, while others may need the facilities which can be provided only in a special school or unit. Both arrangements, however, sometimes appear to leave big gaps in children's development: we expect a great deal of schools, probably making demands which are at times unreasonable.

As an example, we all want our children to become, in some vague sense, "independent." The initiative taken by ASBAH in running independence training courses shows that people feel that this is something which regular education frequently does not provide.

Not everyone has the same ideas about this. Some see independence as a set of simple physical skills needed to cope with everyday life, while others may feel that the most fundamental aspect of independence is earning a living — not being financially dependent on other people.

Both of these are important — if only for self-respect — but real independence is more basic than either. It involves taking decisions about how your own life is organised, both in day-to-day matters and on a more long-term basis.

In her article on hydrocephalus (LINK, March/April), Leonie Holgate mentions skills such as having a bath or getting dressed. Children who develop these skills at school may indeed be unable to perform them elsewhere: for one thing, the special school environment may be organised to make such activities more straightforward. Children who learn the skills at home may simply not use them: it can seem silly or embarrassing or ridiculously time-consuming to keep struggling when people around you could very easily give you that little bit of practical help. It really is very difficult to decide to do things for yourself, without being instructed or assisted,

Independence means having *your* life in *your* hands

when there are always people around who understand your needs.

Most parents will recognise this. It is not just the learning difficulties associated with hydrocephalus, nor the restricted mobility of physically disabled children: it is part of the process of growing up. We tell our children when to go to bed. We get them up in the morning. We give them the right clothes to put on. We put them in the bath. We don't wait for them to come to us and say "I think I'd like to have a bath now — can you help me?" Yet, for a severely disabled person, to make that decision may be the true test of independence — more so than the physical ability to have a bath when told to do so.

Taking responsibility for their own daily routine and, later, having the ability to make more ambitious decisions begins for a lot of children when they go away on holiday without their parents. But for many, the first real progress towards independence comes by moving into a flat, or by going far away from home, perhaps to college or university. In a lot of cases, even today, young people become independent of their parents only when they find new responsibilities and a new kind of interdependence in marriage.

Now these comments apply to everybody, so why do young people disabled by spina bifida have any special needs in this respect? The answer, of course, is that practical physical difficulties loom large, cloud the main issue, and appear to reduce the opportunities for developing independence.

People who think of themselves

as independent do not usually lead solitary lives. Few people would choose to live alone, work alone or go on holiday alone. We all rely on others for company, advice and practical help throughout our lives. But the practical help and specialist advice needed by a disabled person will certainly be different and may well be more extensive than most people require. Independence in this matter means knowing what kind of help you need, either from another person or in the form of a practical aid or adaptation, and knowing how and when to ask for the help.

It is very obvious that it is usually impossible for parents to teach children this kind of independence.

The most valuable situation is one where there are people around who are sympathetic and well-disposed to listen to requests for help, but who are relatively unfamiliar with individual needs. While ASBAH's independence training courses may concentrate on developing specific skills, they also push those who take part into a situation of this kind. A week spent on holiday at Five Oaks or an 'activities week' can be worthwhile when those involved are encouraged to explain their needs and ask for appropriate help.

Some PHAB clubs, other youth clubs and leisure services departments organise holidays or residential weeks which can be used in this way. On a more informal level, there may be friends or relatives with whom a young person could stay for a little while. In some areas, there may be families who would be happy to have a disabled person as a guest for a few days: perhaps this is something which local associations might try to organise.

We need to provide opportunities of this sort, and to be ready to take advantage of them whenever they arise. The growth in independence which can take place in such circumstances is an essential part of education for life: it is at least as important as many of the practical and academic skills which we conventionally think of as education.

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OVER RECENT years there have been several advances in male urinary appliances. Sheaths are now light and designed with wide stiffened outlets so that the risk of

Prince Charles sees how British Rail is helping

THE PRINCE OF WALES was invited to see some of the range of British Rail's facilities for disabled travellers that were put on display at Euston Station on June 14. The occasion also saw the installation of a network of facilities for disabled people at 57 of the biggest and busiest stations.

ASBAH was invited along as part of the press party to comment on the facilities and to meet the Prince of Wales. Representing ASBAH was Denise Dunning (Education, Training and Employment Co-Ordinator) and Maureen Wingrove (from Telesales) who was going to put her wheelchair to the test in the new 'disabled toilets' on the train.

Maureen found that getting on and off the train was easy enough and there was plenty of room for her chair in the allocated space.

However, access within the loo could have been better and ASBAH will be sending comments to British Rail.

There's no doubt that British Rail are living up to their latest slogan of 'trying harder'. They are in constant touch with their Advisory Group on Transport for the Disabled and have made many more improvements to stations and to the rolling stock itself.

But many of you, no doubt, know otherwise! If you have any criticism, helpful suggestions, or even praise about access to British Rail Stations and trains, why not write to them: Bill Buchanan, British Rail Adviser for the Disabled, British Rail, Marylebone Road, London NW1 6JJ.

the sheath coming off, as a result of back flow, is minimised.

Perhaps the development of the Aquadry sheath is the biggest advance in recent years. From our own experiences on Independence Training Courses and from your letters, we know that many youngsters have extreme difficulty managing their own appliances. The reasons for this are numerous but include: poor posture resulting in poor visibility of the area, hand-eye co-ordination problems, perceptual difficulties and difficulties organising what can be a complex task.

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these sheaths as regularly as recommended, once they are fitted securely. Obviously, the solution to these problems would be to simplify the task of fitting the sheath safely and snugly. This is exactly what Raymed hope they have achieved.

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For further information contact Raymed, a division of Chas. F. Thackray Ltd., 47 Great George Street, Leeds LS1 3BB. Telephone (0532) 430028.

MARY SMALL,
Disabled Living Adviser

PUBLICATIONS

PHABulous Journeys

by Dorcas Munday.

Price: £2.35 (including p & p).

Dorcas Munday, Dale Cottage, 129 Midland Road, Wellingborough, Northamptonshire, NN8 1NB.

THIS IS the third book written by a remarkable young woman, Dorcas Munday. It was typed with the aid of a stick held in her mouth, because Dorcas is a spastic, and is in a wheelchair, unable to use her arms or legs.

This is an easy-to-read book telling of Dorcas' exciting travels with PHAB. She is co-leader of her local group. It will help many get their own problems into perspective, and inspire others not to give up hope. The book ends on a thought-provoking note with a look at 'The Future'. What can disabled people do to help themselves, and what can the community do to give support?

Hydrocephalus Fact Sheet

THIS is another information leaflet from ASBAH. Up to 10 copies can be obtained free of charge from National Office. It explains simply what hydrocephalus is, why it occurs, how it is treated, the symptoms that should be looked for, the effects of hydrocephalus and

why different shunts are used.

For other ASBAH publications see page 27.

Furniture Grants

Free from the Welfare Rights Adviser, the Citizens Advice Bureau, The Meeting House, Telford Town Centre, Telford, Shropshire.

This useful leaflet gives guidance on who can apply for a grant for new and second-hand items of furnishings and furniture. If you are disabled and in your own accommodation — whether rented or owned — or planning to move to a place of your own shortly you should be eligible.

Gardens to Visit

Price 70p (including p & p) Mrs K. Collett, "Gardeners' Sunday", White Witches, 8 Mapstone Close, Glastonbury, Somerset BA6 8EY. THE LATEST edition lists private gardens throughout the country that are open to members of the public. It uses the international access symbol to show those places which are accessible to wheelchair visitors.

EARLY in each new year, the members of Soroptimist International of Maidstone start making plans for the Rainbow Club, a Holiday Play Scheme for Physically Handicapped Children in Maidstone and the surrounding area. The idea for the project first developed in 1979 — the International Year of the Child — when thought was being given to an on-going project which would be of benefit to children.

Background

Kent is well to the fore in integrating physically handicapped children into normal schools and school-life. However, one of the problems discovered was that the handicapped children, often drawn from a wide area to attend one or two schools specially suited to their needs are, consequently, rather like boarding school pupils, who do not get to know other children in their home locality as well as they would if they were attending their own local school.

For a child confined to a wheelchair it is often not practicable for him/her to attend one of the locally organised play schemes, nor is he/she readily acceptable into a local group of children for holiday play and the child is, therefore, often virtually isolated during the long summer holidays.

This isolation is often a very great setback to progress made during school time when the child enjoys the stimulation of being with other children. For parents of children enjoying normal health, the summer holidays can prove difficult with the often heard cry of "What can we do now?" How much worse this can be for the parents of a handicapped child, perhaps with other healthy children also in the family.

The plight of one such seven-year-old girl, who was wheelchair-bound, was brought to the attention of our members and with the help and advice of a group of people working with handicapped children, a holiday playscheme, incorporating some able-bodied children, was started, to provide stimulation, fun and above all, play facilities suited to their needs.

It was decided that it would be essential to seek three adult helpers with relevant experience, one of whom with nursing qualifications,

For young handicapped people who have to attend special residential schools away from their own area holidays may not be a particularly enjoyable time. Sometimes they return home only to find that they are

becoming virtual strangers; the more time they spend away at school, the fewer people they know at home. The Soroptimist International of Maidstone saw the problem and decided to do something about it.



Free 'hair-do's' for the Rainbow Club.

PICTURE: South Eastern Newspapers

How the Rainbow brightened up the holidays

who would be paid a sessional fee, and to recruit teenage voluntary helpers from the area, who might be interested in this form of service.

Suitable premises were found and fund-raising was started, and in the space of a few months, the helpers were appointed and a programme of activities was formulated to give 12 four-hour sessions during the summer holidays.

The Early Days

On a sunny morning in July 1979, fourteen children arrived. Some were in wheelchairs and quite severely handicapped and some with little obvious disability, but all of them looking initially somewhat apprehensive.

Quite soon, with the obvious enthusiasm of the helpers, both adult and teenage, the children relaxed. Firm friendships were established and a programme of mutual enjoyment was entered into.

At the end of the first four weeks it was clear that we had found a need among physically handicapped children and had devised a means of meeting that need.

Finance

Each year since the scheme was started, it has attracted increasing interest in the local community and consequently money to finance the scheme has not been a major problem. However the cost is high, amounting to some £1,000 per year. Much of this is used for transport, hiring of premises and sessional payments to the adult helpers and appeals and fund-raising efforts have to be constantly maintained.

Premises/Facilities/Staffing

The Playscheme sessions are currently held in a sports pavilion, rented from the district council, where there are adequate indoor facilities and extensive playing fields, with outdoor play



Visitors, helpers and children of the Rainbow Club

equipment. Toys and other specialised equipment is loaned by a local school which many of the children attend.

The adult helpers consist of an organiser, a play leader and a qualified nurse, together with six to eight teenage helpers at each session. Each year sufficient helpers have been eager to be selected and usually an overall total of fourteen teenagers help over the four-week period. This number allows for some being away on holiday etc. during the sessions.

Some of the children are brought by parents, but most take advantage of transport in the mini bus loaned by the Maidstone Organisation for the Disabled. A few who live further afield are brought by transport provided by a Volunteer Bureau, and club members often fill in the gaps.

Age Range and Programme

Originally the age range was to be five to eleven years, or until a child found wider interests. Subsequently however, we have found a great need for holiday play activity for children from three and a half years. These very young children have been referred, or their parents applications checked, by health visitors and several of the children accepted were suffering from emotional trauma or lack of

stimulation in the home environment.

The helpers have been encouraged and delighted at the way in which children have responded.

The helpers aim to provide an outing each week, using loaned transport. Some of the trips are fairly local but at least one is as far as the seaside. The "at home" sessions are not rigidly planned since handicapped children need constant changes of activity, so the helpers "play it by ear". There is much painting and model making. Dressing-up is very popular as are singing games and impromptu percussion bands — but most of all, the children enjoy the companionship of each other and especially of the teenage helpers with whom they have a great affinity.

Types of Handicap Encountered

The children attending the Play-scheme have spina bifida, muscular dystrophy and atrophy, visual and hearing handicap, cerebral palsy, cystic fibrosis, asthma and metabolic malfunction. In 1983, twenty one such children participated. Some of the children need medication during the play sessions, or skilled but discreet observation, all efficiently coped with by our nurse helper, whose

presence is increasingly realised to be essential.

Visitors

There have been a number of visitors during the sessions and all are welcomed. Health visitors, social workers, teachers and each year so far the Mayor and Mayoress of the Borough of Maidstone have visited the children and all find that after the first few moments of orientation, they become totally absorbed in the fascination of the activities and find it hard to drag themselves away!

The teenage helpers gain much from their contact with the children. They can play freely with them either in groups or in a one-to-one situation and they feel secure with the back-up of the adult helpers. It has been interesting to watch the reactions of some of the young helpers when first coming into close contact with a severely handicapped child. Initially a look almost of horror and then, gradually, great compassion and caring.

Some of our young helpers are now seeking careers among handicapped children. It is not possible to know if they came to help us with this already in mind, or

Continued on P29

RECENTLY described as “a true flagship of the disabled”, a unique sailing vessel is now under construction at an Essex shipyard.

The 400 ton square-rigged barque S.T.S. Lord Nelson, the largest sailing ship under a British flag to be built in a British shipyard for over 75 years, will be unique in that she is the only one to have been purpose-designed to accommodate, and then be crewed by physically handicapped people.

Lord Nelson — aptly named after Britain’s most famous disabled sea hero — is being built for the Jubilee Sailing Trust which for the past three summer seasons has been successfully running voyages in its chartered vessel, the 133 ft. brigantine Soren Larsen, which sprang to fame as the star of the television series “The Onedin Line”.

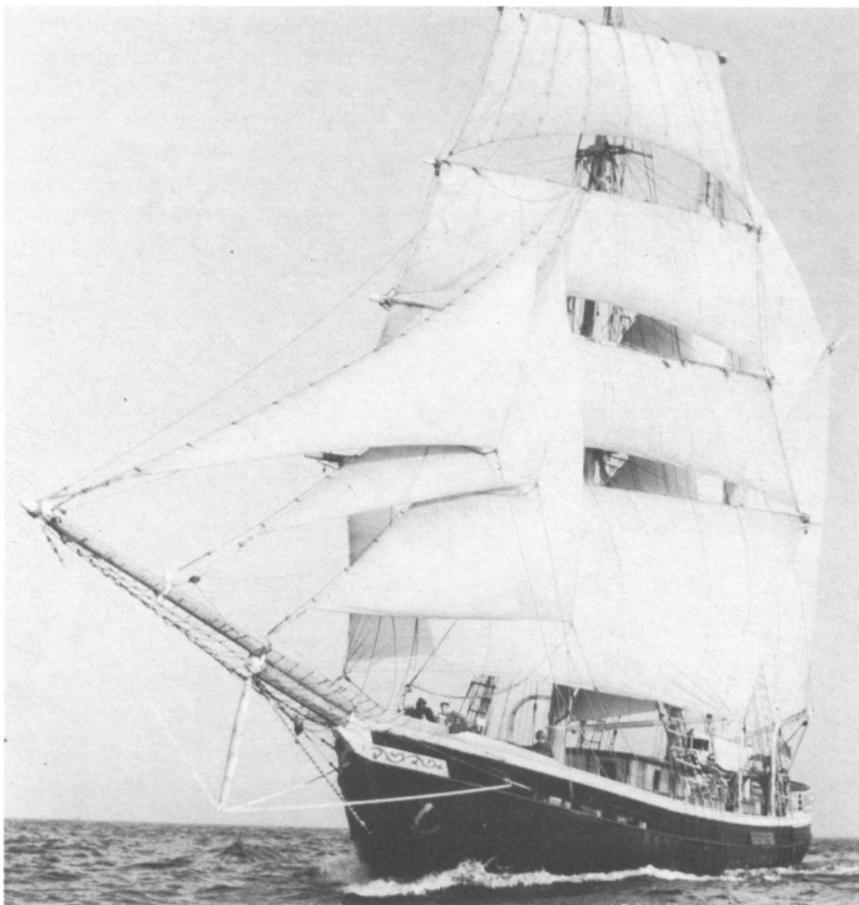
The Trust’s aim is to provide adventure holidays for the disabled of a type which would otherwise be denied them whilst at the same time fostering the integration of the disabled with the able-bodied in sharing the exciting challenge of crewing a tall ship at sea. On each voyage — which vary in length from a week-end to a fortnight — half the voyage crew are physically handicapped.

Many adaptations have been installed aboard Soren Larsen, including wheelchair tracking round the main deck, lifts between decks, a special helmsman’s chair, audio compass for the blind, a hoist to allow the more adventurous severely disabled to get aloft, and, of course, special toilet facilities.

These, and other facilities, will be incorporated in the construction of Lord Nelson which has been designed in such a way that disabled people will have access to every part of the ship, even though in wheelchairs. She will have a permanent crew of seven and a voyage crew of 44 of whom half will be physically handicapped, including up to eight in wheelchairs.

Being built at a cost of over £2m., of which half still remains to be raised, Lord Nelson is expected to be completed in time for next year’s sailing season.

The Trust, which was founded with a donation from the Queen’s Silver Jubilee Appeal, and which now has the royal patronage of Prince Andrew, has made great



SOREN LARSEN under full sail

Jubilee Sailing Trust will open new horizons with the *Lord Nelson*

By MIKE ORDISH,
Press Officer, Jubilee Sailing Trust

strides over the past two years. The launching of Lord Nelson will mark the culmination of a tremendous amount of effort on the part of its officers, its design team and its fund-raising organisation.

The success of the Trust’s voyages in Soren Larsen is reflected in the number of voyagers who have become “regulars”, and it is reflected too in the lasting friendships formed — and comradely friendliness is the keynote of life on board.

All who sign on for the voyages are expected to play their part in the sailing of the ship — from taking a spell at the wheel to heaving on the ropes to operate the sails — to the best of their ability, and they must also take their share of the daily chores from swabbing decks and polishing brasswork to serving meals and washing up. For the disabled all this can result in a very

satisfying sense of achievement, and it can be an equally rewarding experience for their able-bodied companions.

Disabled crew members almost all return from their first voyage with a new sense of confidence. They each have an outstanding experience to remember, such as a climb into the rigging, the silence of sailing on watch on a starlit night, the thrill of buffeting through wind and waves in a heavy sea, but most of all, as one young severely handicapped voyager put it, “my most outstanding experience was just finding out I could do it”.

Anyone interested in sailing with the Jubilee Sailing Trust should contact the Trust at Atlantic Road, Eastern Docks, Southampton SO1 1GD.

ASBAH PUBLICATIONS

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

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

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

Booklets

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

Research Reports

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

All the above prices are inclusive of postage and packing.

Leaflets

Lives in Question.	30p
Information leaflets.	100 for £4
Fact sheets — (on a wide variety of subjects).	up to 10 copies free
Asian language translations of a Fact Sheet about spina bifida and hydrocephalus and ASBAH's work are available free (up to 10 copies) from national office.	
Translations are into Bengali, Gujarati, Hindu, Punjabi and Urdu.	
Welsh language sheets are also available — up to 10 copies free.	

Please send at least 30p postage.

All available from: Information Officer, ASBAH, 22 Upper Woburn Place, London WC1H 0EP.

Cheques payable to "ASBAH".

NB: The prices apply in the UK only. Overseas rates supplied on request.

Magazines

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

Films and slides

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

Scottish Spina Bifida Association

Free leaflets are available from the Scottish Spina Bifida Association (address below): The Association; The Medical Aspects; Scoliosis in Spina Bifida; Employers' Leaflet.

<i>The Spina Bifida Baby</i> , O. R. Nettles, MSCP, ONC.	40p
<i>Growing up with Spina Bifida</i> , O. R. Nettles, MCSP, ONC	35p
<i>Experiences of an Infant Teacher during two years teaching a child with Spina Bifida</i>	5p
<i>Self Help with Spina Bifida</i>	10p (Free to members)
<i>Keeping Fit</i>	10p (Free to member)

Post and packing is extra.

Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW.

Tel: 031-332 0743.

<i>The Social Implications of Spina Bifida</i> , Margaret Woodburn	£7
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Obtainable only from N.F.E.R. Publishing Co. Ltd., Darvilla House, 2 Oxford Road East, Windsor, Berks SL4 1DF. Tel: Windsor 69345.

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Parachuting for ASBAH . . . or . . .

Jump at the chance!

REGULAR readers of LINK will no doubt remember that I have, in the past, frequently written on the subject of parachuting. Whilst I would hate anybody to think that I am obsessed with the subject, I have to admit that as, in principal, one should never ask anyone to do something which one is not prepared to do oneself, there was a memorable occasion, a year or two ago, when I took the extreme step (or leap) of throwing myself out of a perfectly serviceable aircraft, at a height of about 2,500 feet.

It is useless to deny that the experience was disconcerting as one actually exited the aeroplane, or that the basic training of six hours on the day before the jump was demanding, particularly for a person who is as unfit as I am, but it was all worth it for the sheer exhilaration of the descent and the knowledge that it was helping our favourite charity, ASBAH!

I return to the subject yet again, as over recent months it has begun to emerge that throughout the country there are massive and comparatively untapped reserves of people who are both prepared to attempt, and enthusiastic about the idea of doing a sponsored parachute descent and we, at national office, have been busily recruiting members of the police force to take part, confining our efforts to the London area with our recruits travelling to Peterborough Parachute Centre for the course and first jump. However, there are a substantial number of other parachute training schools throughout the country and, indeed, one need not confine one's recruiting to the police force as interest has also been shown by

business executives, barmaids, dustbin men, members of the fire brigade, members of ASBAH's staff – indeed the list is endless!

We have been working on the principal that if people do volunteer to make a first jump, we are prepared to meet the cost of their training course out of the sponsorship raised, provided that this sponsorship amounts to 50% more than the cost of the course. Prices vary from place to place, but on average amount to approximately £60, with more favourable rates frequently obtainable on a group discount basis.

I was happy to learn the other day that the Sussex Association have taken up the idea and produced an excellent leaflet to recruit student parachutists, entitled "Jump at the Chance". Obviously, both Sussex and we will be monitoring their success and judging from our experiences at 22 Upper Woburn Place, the results will be excellent.

Should any local Association be interested in considering this idea as a relatively trouble-free means of



Judy Kay, looking pleased with herself after the jump, we presume, and not before!

raising funds which does not involve any significant investment to get it off the ground (sorry, no pun intended) then I shall be more than happy to do what I can to help and advise.

I will look forward to hearing from you on 01-388 1382 or by letter, confident that, in this case, the maxim "The sky's the limit" really is true.

JUDY KAY
Appeals Director

RAINBOW CLUB: *Continued from P25*

whether helping has stimulated their interest — we like to think that it is a bit of each! But the involvement which we can offer to teenagers is another positive aspect of our playscheme.

We have all learned a great deal about the problems of physically handicapped children and their families and each year we recognise the interaction between the children and all those involved with them, whether they are our helpers, the children's families, or the school staff.

The Future

Having discovered the need it is increasingly obvious that the means of meeting this need must be met and the playscheme continued.

Soroptimist International of Maidstone members will therefore continue to try to provide the means and are encouraged by the fact that an idea launched in the Year of the Child has proved successful and has offered a facility to these children, which may not otherwise have been available to them. We also feel

pleased that not only the children have benefited, but the families on whom there is a very great strain, have, in some way, had a little light relief from the care and worry of looking after these unfortunate youngsters.

The project co-ordinator is Miss Joan M. Perrin, Little Close, Chart Road, Sutton Valence, Maidstone, Kent. Tel: Maidstone 842124.

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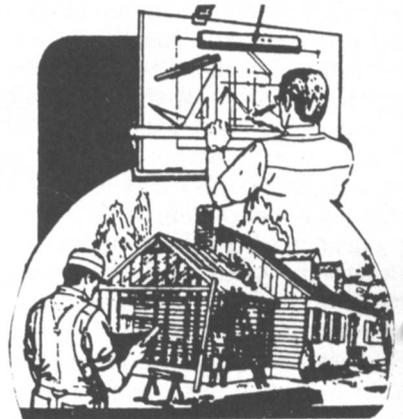
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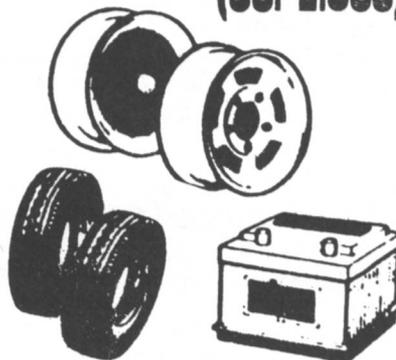
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