Link

Association for Spina Bifida and Hydrocephalus/ASBAH

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Association for Spina Bifida and Hydrocephalus (ASBAH)
22 Upper Woburn Place, London WC1H 0EP

Registered Charity No. 249338 **TEL: 01-388 1382/5**

Patron: HRH The Duchess of Gloucester

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

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Miss Clare Michelmore, *RGN, HV*; Mrs Leonie Holgate, *MCSP.*

Link Editor: Mrs Susan Gearing

Development Officer at Five Oaks:
Mr Paul Cooper *BA (Hons)*

ASBAH Publications

All available from National Office.
Cheques payable to 'ASBAH'

Children with Spina Bifida at School (1985) *Ed. P. Henderson*	95p
Young People with Spina Bifida and/or Hydrocephalus — Learning & Development (1985) *Leonie Holgate*	£1.60p
The Handwriting of Spina Bifida Children (1979) *Joan Cambridge, Eliz. M. Anderson*	£1.60p
Spina Bifida and You — a Guide for Young People (1985)	£3.50p
Sex for Young People with Spina Bifida or Cerebral Palsy (1984)	£1.75p
The Nursery Years (1983) *Simon Haskell, Margaret Paull*	60p
Life and Death — thoughts on bereavement (1983)	75p
Making our Way — individual experiences of young people with Spina Bifida and Hydrocephalus (1984)	£1.20p
Your Child with Spina Bifida *Prof. J. Lorber (1981)*	60p

Booklets/leaflets

General leaflet	Free
Housing: general advice for young people	Free 60p for professionals
Five Oaks leaflet	Free

All prices include post and packing.

Fact Sheets	up to 10 copies free

Translations of fact sheets are available into Bengali, Gujarati, Hindu, Punjabi and Urdu, and into Welsh.
Please send at least 30p postage.

Films and Slides

Appeal for ASBAH (for hire) *16mm colour film (8 mins)*	£4.00p + 60p VAT
Living with Spina Bifida *Slide sets and notes (12 slides)*	£7.00 + 75p VAT

Magazines

LIFT — for members of LIFT (young ASBAH)	Free
Causeway — *for contributors to ASBAH's work*	Free

LINK SUBSCRIPTION

UK	£3.30p
Europe and Overseas Surface Mail	£4.80p
Air Mail	£10.80p

For payments other than in sterling add the equivalent of £3.

* *Except in the case of LINK all the above prices apply in the UK only. Overseas rates on request.*

Editor's Note

RALLY ROUND ASBAH ON ITS 21ST. SPONSOR THE ASBAH CAR AND RAISE THOUSANDS

An ASBAH car will be competing in the Beaujolais Rally in 1987, but hopefully on a much grander scale than before — supported by sponsorship from ASBAH members and friends from all over the UK.

The aim is to raise many thousands of pounds for the work of ASBAH in all parts of the country in this its 21st birthday year.

If every LINK reader could obtain sponsorship of a few pounds it wouldn't be difficult to raise a total of £100,000! What a birthday present!

Sponsorship forms will be ready in mid February, so please do order some and rally round ASBAH!

For forms and further details the man to contact is: Richard Poole, ASBAH, 22 Upper Woburn Place, London WC1H 0EP. Tel: 01 388 1382.

ASBAH has been involved with the rally for the last four years. Read more about it on pages 18/19.

Cheers!

SUE GEARING, Editor

On the INSIDE

MAIN FEATURES

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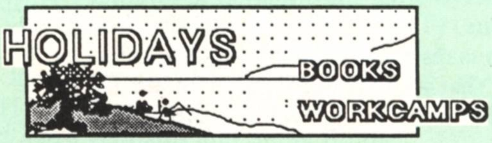
LEISURE



IN THE NEWS

FUND RAISING

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PLUS

COVER PICTURE

A very big moment for Annie Valleader as she talks to HRH The Princess of Wales who was visiting Sussex ASBAH's house in Worthing. See pp 10/11 "Sussex"

Link is published by ASBAH (The Association for Spina Bifida and Hydrocephalus)

Contributions to LINK by way of letters, news, photographs, articles and opinions are warmly welcomed. The closing date for the next issue is February 15. Send to the Editor at National Office.

Letters

Trust your instincts

I am the mother of a hydrocephalic child, Holly, who is four. At the age of 5 months she had a cardiac shunt inserted. We had a few ups and downs with blockages to begin with and she had a revision at 9 months. After that things settled down and she was growing up to a normal, healthy, active child. . . until a year ago when we noticed she'd started to look very close at the TV and books and was falling over a lot more than usual.

We had her tested for short-sightedness, but it wasn't that. After that, they assessed her every few months and discovered her eyesight was deteriorating, but with none of the other symptoms of brain pressure — headaches and vomiting, so I can only assume that the shunt was ruled out. We accepted that she was to be partially sighted due to the original hydrocephalus (or so we were led to believe!)

It wasn't until we went for her yearly check of the valve at the Sheffield Children's Hospital that we asked about the possible link between the loss of sight and there being something wrong with the shunt. . . They admitted her straight away for investigation, and had a scan and X ray which revealed the lower end of the shunt was pulling out as she was outgrowing it. She had the lower end replaced, and now the sight deterioration has been arrested.

The only explanation was that she was outgrowing the shunt very gradually, and the brain pressure wasn't high enough to give her any of the more tell-tale symptoms. . .

However, now that is all behind us and Holly has adjusted to her loss of sight, although she still remains partially-sighted (optic atrophy) which they say might improve slightly given time for the nerves in the brain to recover. . .

I would like this opportunity to tell other parents in a similar situation to question your doctors, eye specialists and whoever, as I wish I had done. Take your child to the hospital that they are under for the valve. Even if it is not that, at least you have reassured yourself, rather than taking what others say to be right.

After all the parents of these children have more insight and instinct that something is wrong with the valve, long before a team of specialists!

MRS B. BLOOD
Scunthorpe.

Poor quality of hospital care

Some while ago I came across a family who had just had a son with spina bifida and hydrocephalus. The condition had been picked up on a scan late in pregnancy and the family had rejected termination and decided to carry on with the pregnancy.

As a professional couple they sought a lot of advice, met the local paediatrician and arranged that the mother would accompany the baby to hospital where he would be treated.

This all went according to plan and they were happy with the treatment that the child received but felt that the quality of the care available for the mother was very poor. The staff were kind to her and a midwife called daily to see her but they felt that the children's hospital was not at all geared to the needs of a post-partum mother.

They are taking this up locally but wondered what the situation is in other regions (They live in Lancs.). The obvious response to their complaints has been that there is too little demand for services to be made available other than at a basic level. They wonder whether demand would be higher if there were good facilities and mothers were encouraged to accompany their babies to neo-natal units.

I don't know of anyone who has done this in the Liverpool area — many of the mothers are so traumatised by the shock that they just want to get home as quickly as possible. On the other hand, with more frequent ante-natal diagnosis, more families will have the chance to be forewarned and to plan things to some extent.

It would be interesting to have readers' experiences and views on this issue and any information on how it is dealt with in other areas.

ANGELA LANSLEY (MRS)
ASBAH fieldworker

Proud parents

Our daughter, Helen, is 18 and has post natal hydrocephalus. She has ha[illegible] numerous set backs in her life.

But two years ago we really thought her life was beginning. Helen started a two year independent course at Beaumont College for the physically handicapped in Lancaster. It changed her life completely. She matured beyond belief.

Unfortunately in May things went wrong with her valve and a cyst which had developed. Seven operations and weeks later, Helen is home and fighting her way back to health. She never complains, never says 'Why me?' or demands our attention. . .

We know there are lots of other young people who have suffered as much as Helen, but we would like her to know how proud we are to have her as our daughter. Also we are grateful to Mr Foy and the staff on Caton Ward at Walto[illegible] Hospital Liverpool.

CAROL EWBANK
Chorley, Lancs.
a member of the hydrocephalus support group.

Opportunites going begging

In your Nov/Dec 1986 issue ("News-line" column), you drew attention to the Spastics Society's report the results of which conclude that employers discriminate against disabled people.

We registered a YTS training opportunity to learn about public relations with the Manpower Services Commission and ILEA on 6 June 1986. Applications from disabled people were particularly welcomed. Indeed a disablement resettlement officer visited Abucon's offices to discuss details with me.

We also placed advertisements in a number of publications supposedly read by disabled people and their advisors and details were circulated to delegates at a conference held for those giving career guidance to disabled people.

But, almost seven months later, we are still without a youngster and not a single suitable candidate has been submitted. This is despite Abucon's numerous telephone calls and several letters chasing ILEA and the MSC for a suitable youngster. I was told by the MSC that young people did not want to take up YTS opportunities in offices in London, and disabled people prefer to stay at college rather than gain "on the job" experience.

So, while I am sure that some people do discriminate against disabled people in employment, there are some opportunities going begging to which there do not appear to be any takers.

LIZA A JONES
M.CAM, MIPR, FECI
ABUCON,
International Business & PR
Consultants,
24 Strutton Ground,
London SW1P 2HR.

21 YEARS 1966 - 1987

ASBAH

STILL LOOKING FOR THE KEY

NATIONAL ASBAH is 21 this year. It has been a period of growth, discovery and maturity — mirroring the development of a significant number of young people with spina bifida and/or hydrocephalus, who have grown up alongside ASBAH.

As the slogan for this birthday year ggests, ASBAH hasn't found all the answers. It is still looking for the key to a good standard of life for those with spina bifida and/or hydrocephalus, for the key to equal opportunities, and, of course, the key to the causes of spina bifida which may unlock the possibility of prevention.

But much progress and development has taken place in the last 21 years, for which ASBAH has been either directly responsible or in which it has played an important role:

- There is much greater awareness by authority and the public of spina bifida and hydrocephalus.
- ASBAH has become a significant national charity with professional staff who have time and expertise to give upport to those with spina bifida and ydrocephalus.
- Families who give birth to a child with these disabilities need no longer feel alone. They can look to their local associations and to national ASBAH for friendship, a wide range of support and counselling.
- There is much more participation in the running of ASBAH and in the development of their own lives by young people with spina bifida and/or hydrocephalus.
- These young people have greater independence and self-knowledge. ASBAH's development of independence training has played an important part in this.
- A separate group for young people — LIFT — has been established.
- Research has been sponsored and supported by ASBAH — to improve quality of life, and to discover more about hydrocephalus and spina bifida. Research indicates that a well-balanced diet, containing the right kind of vitamins can play a significant, if not a vital role, in helping to prevent spina bifida. ASBAH supports further research in this field.
- National ASBAH has developed a wide range of services particularly fieldwork, which has proved valuable to many families, and, more recently, has responded to the need for counselling for individuals and families.
- There has been an increase in knowledge and awareness of hydrocephalus, and special support for those with hydrocephalus alone.
- Five Oaks, ASBAH's Centre in Yorkshire has been established and developed.
- International links have been formed, leading to the setting up of an International Federation for Hydrocephalus and Spina Bifida.
- Local associations have grown up all round the country giving a wide variety of support to families in their area, and forging links with National.

The last 21 years has been significant for disabled people in general. There has been a growth in acceptance of disabled people by the public — of their rights and needs — and we have seen the beginning of much greater participation by disabled people in life in general and in the shaping of their own destinies. Generally speaking, facilities and equipment have improved.

The introduction of prenatal screening and testing has led to the possibility of the termination of pregnancies where the fetus has a neural tube defect. It has also given many 'at risk' couples the confidence to try and have a child, or to increase their family.

Much discussion has taken place, and will no doubt continue for a long time, about termination of pregnancies, and also, running parallel with this, about the rights of newly born babies with severe disabilities.

The improvement in prenatal facilities has led to an increase in the number of premature babies being born and surviving, but this has given rise to another problem — an increase in the number of such babies developing hydrocephalus.

ASBAH has taken a good look at its work in the light of these developments and the present situation, and will be taking steps to improve and extend its services.

It hopes to forge a more beneficial relationship with the local associations so that the ASBAH movement as a whole can go ahead into its adult life greatly strengthened and to the benefit of all those with spina bifida and/or hydrocephalus.

The Education Act 1981: Four years later

It's been an education — and not a very pleasant one!

by Mrs Denise Dunning

ASBAH's Education, Training and Employment Co-ordinator

IT is four years since the implementation of the 1981 Education Act.

For some children, parents and teachers this has meant fear, frustration and fortitude:—fear, in that many teachers were unaware of disability and how to cope with it; frustration of parents in trying to understand the complexities of the assessment procedure; and fortitude of both parents and children in pushing forward for the appropriate educational provision from their local education authority.

The problems have been wide-ranging: lack of information provided by local education authorities (LEAs) concerning assessment procedure; lack of resources in mainstream schools, lack of knowledge of teaching staff concerning a child's special needs.

Assessment procedure

Understandably, many parents need time to come to terms with handicap and, therefore, many are reluctant to have their child assessed. They feel the child will be 'labelled' for the rest of its life. Parents are also concerned that if their child is accepted into the nursery unit of a special school that he will have to stay in the special school for the duration of his education.

Parents are not always aware of the procedure regarding assessment. One parent was told by her GP that she should not have her child assessed; the parent believing the GP was the 'fountain of all knowledge', did not pursue the matter further.

If parents want their child to be assessed they must write to their local education authority requesting assessment of the educational needs of their child (under Section 5 of the 1981 Education Act). The parents need not give reasons for this request.

Once an authority has decided to assess, they should send a formal notice to the parents confirming this decision, and giving details of a 'named' officer, whom the parents can contact for further information.

It is the usual procedure for an educational psychologist to visit the parent and child in the first instance before the full assessment is undertaken. If parents are unhappy with the report of the educational psychologist they can ask for a second opinion which means they can request an assessment of their child by another educational psychologist within the same local education authority.

The Association of Educational Psychologists strongly supports the right of parents to seek second opinions where they feel this to be necessary and stresses that opportunities should be available for such second opinions to be provided at no charge to the parent and from a fully qualified educational psychologist.

Opportunities do exist in a minority of local education authorities for a reciprocal arrangement between neighbouring LEAs to allow an educational psychologist from one authority to offer a second opinion on behalf of a parent in another authority.

Parents may not be aware that there is an Independent Panel of special education experts which is able to give parents a 'second opinion' when they have doubts or anxieties about the way in which their child is being assessed or when they wish to appeal against the provision made by the Local Education Authority under the 1981 Act. There is, of course, no guarantee that the views of the members of the Panel will be identical to that of the parents, but they will seek to reflect the views of the parents. The Panel is [illegible] voluntary service and families will only be expected to m[illegible] expenses incurred by Panel members. It is a confidential service. (See below).

Attitudes

Often it is the attitude of the Heads of schools which is of paramount importance in the integration process.

There are a number of Heads who take a great interest in their pupils with special needs and are in contact with ASBAH for advice and guidance on how best these can be met.

Moving area

When parents consider moving house it is always advisable to look at schools in the new area, and arrange to visit informally.

Parents should not automatically assume that provision under one LEA is going to be the same under another. For example, it may well be that one LEA will provide welfare assistance for ten hours a week — in another authority thi[illegible] provision may be non-existent. Failure to contact anoth[illegible] LEA in respect of transferring of schools can lead to frustration and delay.

Problems

If a child has been assessed and enters mainstream school but problems occur, the first step is for the parent to ask for a meeting with the Head.

If the problems at the school affect other children with special needs, i.e. lack of welfare provision or inappropriate adaptations, then the parents of these children should get together to discuss further action. They should request a meeting with the school governors, and also write to the Chairman of the Education Committee expressing their concern.

Another area which often causes concern is when a child transfers from junior mainstream into secondary. It often happens that the secondary school is a large comprehensive which may not be fully accessible. This means the child may have to attend a 'designated' school. A 'designated' school is a mainstream school which has been designated by the local authority to take pupils with special needs because the school (hopefully) has been fully adapted to meet those needs.

The Education Act 1981: Four years later

The Centre for Studies on Integration in Education

The CSIE, an organisation established under the umbrella of The Spastics Society, has published the results* of a survey of the 104 local education authorities throughout England and Wales. (65 authorities (i.e. 63%) responded). The aim of the survey was to discover exactly what LEAs were publishing in the form of booklets/information packs explaining the 1981 Act to parents.

There were two significant findings:

(a) failure by many LEAs to explain the key aspects of the whole assessment procedure;

(b) failure by a minority of LEAs to produce any information material at all, for parents.

In more detail, here are a few examples of what LEAs failed to tell parents:

(1) only 6% listed parents' duties under the Act

(2) only a third told parents they had a right to be fully consulted and to receive all relevant information

(3) over half failed to mention to parents that they had a right [illegible] request a formal assessment themselves

(4) only 51% referred to the 'named' officer when a formal assessment was served

(5) more than half (54%) failed to refer to annual reviews after a Statement had been made, and two-thirds (62%) did not mention the re-assessment process at 13/14 years

**The Report 'CAUGHT IN THE ACT' is available from CSIE 16 Fitzroy Square, London W1P 5HQ. Price £3.50. (Excerpts from the report were printed here courtesy of CSIE).*

Department of Education and Science Research

The DES has recently funded a 1981 Education Act Research programme. The research was undertaken by three bodies:

(1) The National Foundation for Education Act Research in England and Wales which looked at 'Meeting Special Educational Needs: Support for the Ordinary School';

(2) Huddersfield Polytechnic/Manchester University [illegible]roject Impact' (the development and evaluation of a modular diploma); the development and evaluation of short courses, and a follow up study of the Education of the Developmentally Young package.

(3) University of London — Institute of Education Policy and Provision for Special Educational Needs

The research by the NFER examined mainstream schools and studied (a) links between special and mainstream schools, (b) local authority support services, and (c) in-service education.

Secondly, the Huddersfield Polytechnic/Manchester University evaluated a new postgraduate diploma in special educational needs which had only been available in the North West.

Thirdly, the University of London, Institute of Education studied the effects of implementation of the Act on policy and provision.

The research was aimed at offering guidance to the DES on the ways in which legislation is being implemented and pointing out where changes should be made.

At a conference in November to publicise the findings of the research, Mr Dunn, Under Secretary of State for Education, said that the survey showed that some LEAs had made enormous strides to improve provision but regretted that this practice was not consistent throughout the country. He considered there was a fundamental need for cooperation between all professionals and elected officers of LEAs. He emphasised that there was still a need for improved communication between parents of children and statutory authorities.

He felt strongly that voluntary bodies could offer valuable help to both parents and LEAs, and that LEAs should remember that voluntary bodies were willing to play a more active part.

To highlight one or two points from the University of London research, it is interesting to note that of the 79% of the LEAs who responded, 53% said that they always carried out an assessment if asked by parents.

With regard as to who, within the LEA, takes the decision to assess, 56% said that it was by an administrator!

Length of time for statementing procedure varied between 40 weeks to a year. The research revealed that LEAs gave the delay in submission of medical reports as the main reason for lengthy statementing procedures.

The research also highlighted the fact that many teachers in mainstream schools needed more support staff to assist children with special needs.

It Pays to make a noise!

Whatever research is undertaken, as always it seems to be that the parents who make the most noise are those who receive the most satisfaction.

Independent Panel: Contact Ann Hollings Administrator, Independent Panel, c/o 20 Compton Terrace, London N1 2UN.

Continued over page

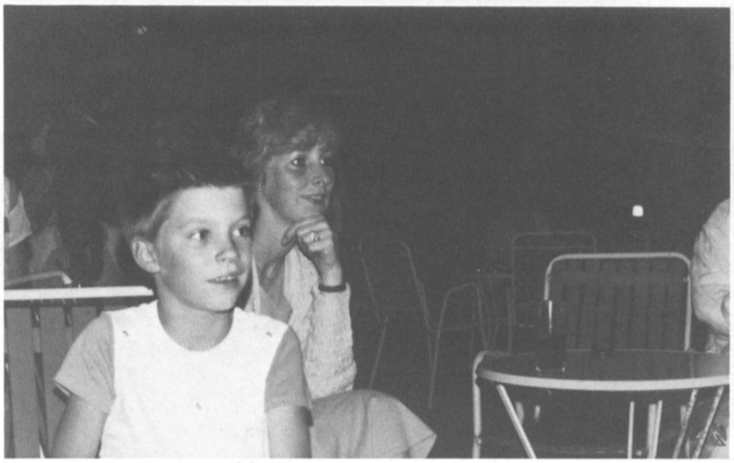
The Education Act 1981: Four years later

Continued from page 7

Personal story

Getting into the mainstream

Mrs S. C. Day,
West Wickham, Kent



Mrs Day and son Paul

As a mother of an 8 year old spina bifida boy, I know from personal experience the struggle, heartache and worry caused by wanting to have a handicapped child integrated into a mainstream school. I hope that perhaps my story will give encouragement to those facing similar problems.

Firstly, let me say that my son is fortunate in as much as the only evidence of his handicap is double incontinence. Consequently he wore pads.

When Warren reached school age numerous meetings were held to discuss how to overcome the problems that arise from having an incontinent child in a 'normal' school. Apart from the fact that I was made to feel that I was being totally unreasonable to expect the local authority (Bromley) to provide the necessary help, my child was discussed in terms of an obstacle to be overcome any way possible, regardless of his feelings or mine.

Although Warren was never statemented, a psychologist did make a home visit and said that my son should carry out his full-time education in a mainstream school. I hasten to add that this decision didn't have much impact on the case.

To cut a very, very long story short I visited the school once a day to change Warren's pad and an auxillary nurse, and a member of staff from the local Shaftesbury Society did the same. This arrangement continued for 2½ years (until my younger son started school). I then decided that the time had come for Warren and myself to lead independent lives, just like 'normal' people.

After consultation with my local MP who in turn spoke with the Education Dept. I was told that my services were no longer required at the school, Indeed it was said that the authority h[illegible] assumed I was quite happy with the existing arrangement!

It all seems a very long time ago now, but in fact, only just over a year. Warren happily has overcome his bladder incontinence with an artificial urinary sphincter and no longer wears pads. I happily am a 'normal' wife, mother and Parent Governor at my son's local mainstream school!

At this point I would mention that all along ASBAH were truly supportive to me and gave me the encouragement and strength to fight for what is rightfully ours and our childrens.

Reading Matter

Coping with Disability

by Millicent Isherwood

WELCOME to another in the *Coping with. . .* series. This is a practical and also a very readable guide on how people with disabilities can cope more successfully with the problems imposed by their handicaps.

The introduction describes it as a book which is 'a series of signposts' pointing to helpful agencies, special aids, tactics and strategies.

The author was disabled by polio in 1947 at the age of 22.

Price £2.95. 10% discount on order of 10 or more, 15% for 20 or more and increased discounts for larger orders. Published by Chambers. Available from bookshops or from Chambers, 43/45 Annandale Street, Edinburgh EH7 4AZ. Tel: 031 557 4571.

Their Stories So Far. . . Seven autobiographies.

by the Scottish Spina Bifida Association (SSBA).

TO CELEBRATE its 21st anniversary in 1986 the Scottish Spina Bifida Association has published this simple and interesting record of the lives of seven very different people with spina bifida and/or hydrocephalus in Scotland. They range from Aunt Kit, the oldest member who is 92, to a doctor who has already packed a great deal into her life and still plans to achieve a lot more.

Price £1 (non members of SSBA) and 50p to members. . . (see publications list on next page).

Are you Cooking Comfortably?

by Ann Macfarlane

THIS is an attractive, well designed publication containing a selection of Ann Macfarlane's favourite practical recipes — all of them very simple and mainly using convenience foods. They look as though they would taste delicious! The book has a useful easel stand, and a good glossy coating that would make it easy to wipe if its used by messy cooks!

Ann Macfarlane has been severely disabled with rheumatoid arthriti[illegible] since she was a child. The book[illegible] sponsor is British Gas.

Price £2.95. Published by British Gas. Available from WH Smith and other leading newsagents.

VIDEO

Door-to-Door.

FOLLOWING the success of its book about transport for the disabled of the same title, the Ministry of Transport has now released a 15 minute video. It is not a video of the book, but shows different forms of public transport and how it can be used by people with various disabilities. The aim is to encourage disabled people to get out and use all public transport facilities.

It is on loan free from the Central Film Library, Chalfont Grove, Gerards Cross, SL9 8TN. Tel: 02407 4111.

For more information about the video contact Anne Fry at the Disability Unit, of the Ministry of Transport. Tel: 01 212 4431.

Reading Matter

All Change

a consumer study of public transport handicap in Greater London, carried out by GLAD (the Greater London Association for the Disabled).

THE SURVEY asked Londoners to state whether they experienced difficulties in using public transport, and if so, whether this arose from a physical or mental impairment. This technique of self-definition provides *minimum* figures of transport handicapped people since nobody invented their problems, and many may neglect them because they have come to accept them. The physically handicapped are seen as part of a society which has mobility problems — eg. the elderly, mothers with young children etc.

The report reveals that over 7% of Londoners — at least 465,000 people — are handicapped in their use of public transport. It calls upon Government to acknowledge the need uncovered by *All Change* and to ensure that additional resources are made available to meet it.

Price: £6 plus 15% post and packing from GLAD, 336 Brixton Road, London SW9 7AA. Tel: 01 274 0107.

Charities Administration

from ICSA — the Institute of Chartered Secretaries and Administrators.

LOOSE-LEAF and updateable, this reference book aims to provide a comprehensive and practical source of information for everyone concerned with the administrative aspects of charities. It has been edited by a team of experts from among the ranks of ICSA members. It copes with problems that are likely to arise when forming and running a charity, and looks at activities such as fund-raising and public relations. As such it is a comprehensive source of reference for the professional adviser.

Price: £55. Published by ICSA. Available from leading booksellers.

In our own right — beyond the label of physical disability.

A resource pack produced by Community Service Volunteers.

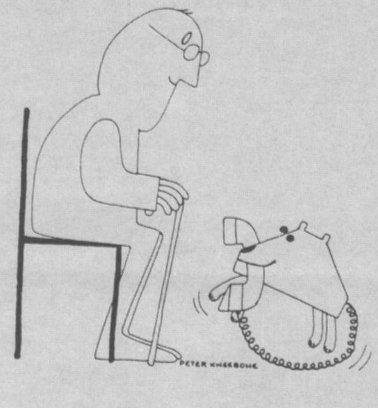
THIS is an interesting and exciting resource pack which should be well received in schools and sixth form colleges. It is aimed at 14-18 year olds studying humanities, home economics, craft and design technology, physical education or for the Certificate of Pre Vocational Education.

It can also be used as a training package for staff who work with physically disabled people, trainees in social work or nursing, housing departments, libraries and volunteers.

The idea is to get these 'key' people really understanding the feelings, aspirations, needs, strong points and weaknesses of disabled people.

It can be dipped into, and one of the eight sections such as mobility and access or education integration, studied on their own before moving on to another. There is also a good Projects section with practical ideas for useful projects that could be undertaken by a group of students.

Price: £9.50 plus £1.18 post & packing. Available from CSV, 237 Pentonville Road, London NW1 9NJ. Tel: 01 278 6601



How to Start a Dial-A-Ride

by Trevor Meadows, Director of the National Advisory Unit for Community Transport.

THERE are now some 120 Dial-a-Rides in the UK and, with the help of this book, there could soon be more. It's a down-to-earth, hard-headed guide for any local authority or voluntary organisation generous enough to aim at starting a Dial-a-Ride. It also has a great deal to offer existing schemes which find some of the problems hard going.

How to start. . . begins with the details of planning — assessing needs, deciding on the type of service, planning the image, relating to other organisations, raising funds. It then deals with the staff and office equipment, booking and scheduling, choosing a vehicle, maintaining it, tax, insurance and vehicle regulations, the launch, budgeting, consideration of radio and computer.

Price £5.50 plus 40p post and packaging from the publishers — ERICA (European Research into Consumer Affairs), 8 Lloyd Square, London WC1 X9BA.

The Young Disabled Adult:

Report of the Royal College of Physicians

In this report, Dr J F Harrison provides an invaluable picture of residential care currently provided in NHS Young Disabled Units, Local Authority Homes, the Spastics Society and the Leonard Cheshire Foundation.

For the first time the differences in the populations catered for, admissions, policies and the effects of different philosophies, are clearly spelled out.

Perhaps the most telling criticism in the report is of the policy of creating Young Disabled Units within the NHS in the early seventies, with no clear idea of their purpose other than to satisfy Parliament's wish to separate younger patients from the elderly.

Dr Harrison's report shows that individual YDU's vary widely in their policies, eg whether planned short stay should be a key feature, or whether rehabilitation is appropriate. He concludes that their role needs urgent review, especially their provision of long term care.

Far more co-operation is required between different care providers to ensure in any area adequate provision of: planned short stay; rehabilitation; committed long stay; the ability to respond to emergencies; and terminal care.

Although most of the analysis is from the point of view of service providers, Dr Harrison chronicles the rise of self-determination programmes in residential homes and of the independent living movement, and argues forcefully for more rational allocation of money between residential care and help in people's own homes. Yet he dismisses the consumer approach fairly quickly on the grounds that it would lead to inequalities or wrong choices. While Dr Harrison is obviously on the enlightened wing of his profession, it does seem a pity that the Royal College has not involved disabled people directly in its recent research and publications. It is quite common these days for research of this type to be published with an appendix of critiques from a selection of people concerned, both professionals and consumers; this would greatly help the formulation of common objectives and programmes.

Copies of the report are available at £4.95 per copy from the Royal College of Physicians, 11 St Andrews Place, London NW1.

Review taken from the RADAR Bulletin

Local Association Round-up

Sussex

(See also photo on front cover). HRH the Princess of Wales visited Sussex on December 3 and took time to call in at No 5 Grand Avenue, Worthing the house for young people with spina bifida and/or hydrocephalus run by Sussex ASBAH (see the last LINK).

It was an informal visit and the Princess was able to meet and chat to all the residents and visited their rooms.

The Princess looked at Chris Rendell's large collection of soft toys and asked if she took them all to bed with her. Chris said she did when she lived on her own. When the Princess saw Jane Denness' television, she asked Jane what had happened on East Enders the previous night as she had missed it.

Mandy Brooks presented the Princess with a cushion — heart shaped and beautifully embroidered. Mandy attended the school of needlework at Bookham, Surrey for several years, and sent a gift to the Princess when she was married.

Little Annie Vallender was waiting in the driveway of No 5 to present her own posy to the Princess as she left. She had only come out of hospital a few days before, but was determined to be there. Annie's father is treasurer of the house project committee.

Sussex Association received a letter from the Princess a few days later thanking them for making the visit such a memorable and relaxed occasion.

LIFT PAPER
What do you think ASBAH should be doing **is the subject of a LIFT paper, following discussion at the 1986 LIFT conference. Free from the LIFT office at National ASBAH.**

(above) A bridesmaid of determination . . . 4 year old Rebecca Ellison of Riseley, Bedford. It took a lot of courage and effort by Rebecca to walk down the aisle and back again on her calipers with her walking frame. But she managed it in fine style and made her parents extremely proud of her.

Scottish Spina Bifida Association

190 Queensferry Road
EDINBURGH EH4 2BW

PUBLICATIONS

The Spina Bifida Baby
By O.R. Nettles, NCSP ONC..40p

Growing Up with Spina Bifida
By O.R. Nettles, NCSP ONC..35p

Experiences of an Infant Teacher during two years spent teaching a child with Spina Bifida..5p

Self Help with Spina Bifida...............10p (Free to SSBA members)

Keeping Fit...10p (Free to members)

Their Stories So Far. . . (7 Autobiographies)........50p to members
(see review on page 8).......................................£1.00 to non-members

Free Leaflets available: The Association, The Medical Aspects, Hydrocephalus, Scoliosis in Spina Bifida, Employers Leaflet

The ASBAH group which enjoyed the Lord Mayor's Show in such fine style (See below).

'The best view in London'

A GROUP of young people from ASBAH had a special invitation to enjoy the best view in London of the Lord Mayor's Show in November. They were invited by the Manager of the Tavistock Square Branch of the National Westminster Bank where ASBAH banks.

Three windows on the first floor level of the bank premises had been reserved for ASBAH and were right opposite the Mansion House where much of the main activities of the Show were centred.

"The Lord Mayor's procession consisted of 138 different items depicting the life of London, and comprised everything from military bands to decorated floats; and from youngsters in costume to city dignitories in splendid carriages. The atmosphere was one of fun and friendship . . ." reports Peter Herrin one of the fathers who went to the Show with his 15 year old daughter Anna, who is a LIFT member.

The Bank was kind enough to supply a splendid buffet lunch for all the guests, and the bank staff, who were there with their families, were helpful and friendly. All in all it turned out to be a very enjoyable family day.

Irish Association opens footwear and caliper repair service

BECAUSE of numerous complaints about the provision of footwear and caliper repairs in the Republic, the Irish Association decided to solve the problem itself. It set about building a workshop on land next to its centre in Clondalkin, Dublin.

The building, which also houses the Association offices, cost £100,000 and was funded by voluntary subscription from branches in the Republic, and a great many friends. A grant was also received from the Department of Health.

The workshop has been operating since early last year and it wasn't long before an average of 10 families were going there each week for repairs to calipers, footwear or other appliances, to buy new footwear, and to have necessary adaptations carried out. The workshop is equipped with the most modern machinery and tools and the staff are experienced technicians.

At the end of September, the Centre was officially opened by Mr Barry Desmond, Minister for Health.

Local Association Round~up

Somerset

THE LAST LINK mentioned the achievements of two young people with spina bifida who did well in the first World Games for Disabled Youth in Nottingham. We have now received a photograph and details of the success of Lisa Harnwell — who was 13 at the time — from Minehead, Somerset.

Lisa who has been competing nationally for some time recorded a first in discus, throwing 12m 44, for which she gained a certificate. She also came second in shot putt with a distance of 4m 92. Lisa, who goes to West Somerset School in Minehead said "There was a very friendly atmosphere and I met a lot of nice people. It was a very good experience". George Earl, Chairman of Somerset ASBAH commented "We are all very proud of Lisa in Somerset".

Lisa Harnwell throwing the discus.

Trafford & Salford

SIR HUGH ROSSI, one of ASBAH's Vice Presidents and former Minister for the Disabled laid the foundation stone of the Stepping Stones project in Stretford, Manchester on November 10 on behalf of Trafford and Salford ASBAH.

ASBAH's Chairman, Mr Robin Mackenzie, and the Executive Director, Miss Moyna Gilbertson were at the ceremony, as well as the Rev John Banks, Chairman of the Manchester Housing Association, which is building the development, other representatives from the Association, the Mayors of Trafford and Salford and members of Trafford and Salford ASBAH.

The Stepping Stone Project will consist of four wheelchair adapted flats in a 12 flat development being built in Cyprus Street, Stretford, by the Manchester Methodist Housing Association. The remaining flats will be for tenants chosen by the Housing Association.

The Stepping Stones flats will provide first homes of their own for young people with spina bifida and hydrocephalus in the Manchester area. They will have the support of the Trafford and Salford ASBAH, and each flat will be linked by phone to a central emergency control.

There will be two single bedroom flats, a flat with a double bedroom, and another with two single bedrooms. This variety should cater for the needs of single people, friends, or a married couple. The flats will be managed jointly by Manchester Methodist Housing Association and Trafford and Salford ASBAH who will choose the tenants.

The need for accommodation of this kind became apparent to ASBAH members several years ago, and with the support of many individuals and local organisations such as Urmston & Davyhulme Silver Band, Flixton Carnival, Sale & Urmston Lions Clubs the appeal was launched. Money is still needed for the fund, which will equip and maintain the four flats.

The whole development should be completed by the Autumn of 1987. The scheme will also include an office for Trafford and Salford ASBAH. *(See photos above right)*

(Top) Sir Hugh Rossi at the laying of the Foundation Stone of the Stepping Stones project in Stretford Manchester. With him are three young members of Trafford & Salford ASBAH (from left to right): Melissa Brazendale, Marcia Summons and Jamie Lee Hatton.
(Above) Chairman of Trafford & Salford ASBAH, Mrs Jean Black, with the three girls again.

Sitting comfortably with a new wheelchair cushion

A NEW WHEELCHAIR CUSHION designed by Reg Dyson of Kennick Medical is the result of ten years experience of the seating needs of the disabled.

Measurements were taken of about 340 bottom shapes and extensive testing of the cushion on most of the neurological, spinal and rheumatiod conditions revealed a need not only for safe seating, but also for:

> *tilt facilities; better ventilation of the genital area to prevent cystitis; a low pressure area under the scrotum in males; a urine drainage channel for occasional incontinence; better ventilation for the skin of the buttocks; and maintenance of a constant ambiant temperature*

After intensive reseach and testing, all these needs were incorporated into one cushion — the Varyflow — which offers coolness, safety and comfort.

Other cushions designed by Reg Dyson have been widely used throughout Britain by the NHS, and in America, Europe and Australia. He has worked as a general nurse and specialist in orthopaedic nursing and is well known for his research into the causes and prevention of pessure sores. (See advertisement on page 17).

Some recent advances in research and practice of paediatric neurosurgery

CARYS M. BANNISTER
Department of Neurosurgery, Booth Hall Children's Hospital,
Manchester.

This article first appeared in Federation Focus the magazine of the International Federation For Hydrocephalus and Spina Bifida (IFHSB).

MANY OF THE diseases affecting the brain and spinal cord of infants and children are the same as those in adults, but they occur with different frequencies and affect different sites in the two groups. In many children's neurosurgical units development defects account for the greatest number of admissions; head injuries, tumours and vascular abnormalities of the brain and spinal cord accounting for the remainder. It is not surprising that in the past and at present the research projects of many of those concerned with children's neurosurgery have been directed towards trying to find out the causes of developmental abnormalities and how to remedy them.

Much has been written and said about many of these projects, for instance the role of vitamins in the causation of spina bifida, and the production of new shunt systems to control hydrocephalus, but I would like to describe another development which already has had, and will in the future substantially effect the management of patients and direct the lines of research of many of those concerned with the neurosurgery of children.

The development I am referring to is the present ability to image the brain and spinal cord with increasing clarity by an ever increasing number of methods; X-rays (CT scanning), ultra-sound waves (US scanning) and magnetic resonance (MR scanning).

In many ways it is US scanning which is presenting the greatest challenges to Neurosurgeons with a special interest in children's diseases because while all the methods image the brain and spinal cord *after* birth, only US scanning can be used to image the brain *before* birth. Modern US scanners can image the fetal head as early as the eighth week of pregnancy, although the pictures obtained are still not detailed enough to indicate whether development is normal or not. By the 16th or 17th week of pregnancy the chambers (ventricles) of the fluid system of the brain and the spinal cord can be seen if the fetus is lying in an optimal position. Abnormalities of the brain and spinal cord can often be detected shortly after this time.

New options are thus available to the parents of the abnormal fetus; they may choose to terminate the pregnancy but, if they choose to continue it, then the development of the fetus can be followed by repeating the US scans at intervals. Gradually more knowledge is being gained about how developmental defects progress as the pregnancy continues and new information is being gathered about when some of them actually appear for the first time.

One of the questions raised by US scanning is whether treatment of the fetus which is still in the womb would be possible or helpful. Two conditions affecting the brain and spinal cord have been considered to date, namely hydrocephalus and spina bifida. Already in about 40 cases fetuses with hydrocephalus have had shunts placed in their ventricles to drain the cerebrospinal fluid (CSF) into the fluid filled cavity of the womb. Many problems were encountered and it is still far too early to say whether the treatment was effective or not. More work needs to be done on a few carefully selected cases and in the laboratory before this procedure is carried out more widely than at present.

In the laboratory experiments have also been carried out to see if it is possible to repair the back of animal fetuses with spina bifida-like lesions. This work is at a very early stage, but it will be of great interest in the future to see what results it produces.

Recent advances in the care of premature babies have lead to them surviving in much larger numbers than formerly and it is now possible to keep babies alive who are born as early as about the 26th week of pregnancy. Both US and CT scanning have shown that these babies are liable to develop haemorrhages into the fluid system within the brain, and that this can later cause hydrocephalus. Much research is being carried out to try to discover exactly why these babies have haemorrhages, and how they can be prevented. Investigations are also being carried out to find out how and when the hydrocephalus in these babies is best treated.

In all children who have had shunts inserted for the treatment of hydrocephalus, the ability to image their brains by one of the above methods may play an important part in the assessment of the function of the shunt.

Before the soft spot on the top of the baby's head has closed, US scanning can be used to measure the size of the ventricles. After the soft spot has closed, US scanning cannot be used because it has to have a window in the bony skull to "look through". Thus in the older child CT scanning has to be used to measure the size of the ventricles. Unlike US scanning, it can also be used to look at the brain around the edges of the ventricles to see if there is any swelling, for if there is it may be an indication that the valve is mal-functioning.

MR scanning is still not as widely available as US and CT scanning, and therefore it has not generally been used very extensively to investigate hydrocephalus. However, it has been shown to be able to image cysts within the spinal cord better than any other means, and it also images very clearly many tumours of the brain and spinal cord.

Whilst recent advances and research have provided solutions to some problems, much has yet to be done. The goal sought by all is to find a means of preventing the conditions from occurring at all, but until that has been achieved many challenges remain to be dealt with.

A recent ASBAH financed research project has brought out the urgent need for district Handicapped Adult Teams to cope with the many health and social needs of physically handicapped adults. At present these young adults can easily become forgotten by the statutory services when they leave school.

The research also showed the need for a resource worker — such as an ASBAH fieldworker — based in the community and giving support and information and providing a link with the proposed district-based adult team.

The research team from the Charing Cross and Westminster Medical School Community Paediatric Research Unit — Dr Martin Bax (paediatrician), Mrs Kay Coombes (speech therapist), and Dr Andrew Thomas (research psychologist) — is currently discussing with the DHSS the viability of establishing these new Handicapped Adult Teams.

Dr Andrew Thomas spoke about the research at ASBAH's recent Conference, and LINK is pleased to carry a summary below:-

Growing Concern

Background to the Study

As a result of the Court Report ten years ago, District Handicap Teams were set up. These are multi-disciplinary teams concerning themselves among other things with the assessment of mentally and physically handicapped children, and the co-ordination and provision of treatment and advice. The teams are intended only for *children.* However, the Court Report considered that the transfer of health care from the child to adult-oriented services was a cause of much concern and recognised the need for flexibility in determining whether a young person should continue with paediatric health services or transfer to adult health services.

A 1985 Study by the Research Unit indicated that some flexibility had been exercised, and nearly half of the 119 District Handicap Teams were prepared to see young people over the age of 16. However, this dropped to only 14% of the teams prepared to see the handicapped adult by the time he or she had reached 20 and over. The problem was also the lack of provision for those young adults in areas where there were no teams, or where no flexibility had been exercised.

"After the age of 16 the amount of contact a handicapped person has with the health service rapidly declines".

The Study

Concerned by this apparent lack of contact with the health services the team took two health districts — Paddington and North Kensington in London, and Wycombe in South Buckinghamshire — and carried out a detailed assessment of the young people's health and social status. The team saw 111 young adults aged 18 to 25. (47 had cerebral palsy, 19 spina bifida, and 45 — other handicaps). The sample was biased towards those with more severe handicaps. 90% of the sample were moderately and severely handicapped. As a consequence only 9% were in further education, 10% in open employment, 2% in sheltered work, 50% were attending day centres or adult training centres, and 29% were at home with no full-time occupation.

Health Care

"Although young people with physical handicaps are likely to have a number of recurring health problems, in general they don't have a standing arrangement or check-up with their GP".

About half the sample was dissatisfied with the service provided by GPs especially since they often reported to be unfamiliar with physical handicap. *"This is probably quite likely to be true as it's been suggested that a GP in an average practice is unlikely to see more than one, or perhaps two at most, spina bifida patients in his or her entire career".*

A specialist hospital doctor is usually a more appropriate person to supervise the health care of a moderately or severely handicapped young person. However, 40% of the sample had not seen any hospital doctor for over two years. *"Given the extent of their handicaps this is a very long time indeed".* About two-thirds of the sample were receiving regular hospital treatment before the age of 18, and only just over a quarter after leaving school.

"One could argue that this lack [illegible] contact with the health services reflects handicapped young people having few health problems and not needing the services of health professionals. Unfortunately, I think the reverse is true".

Of the total sample, 60% were considered by the paediatrician to have moderate or severe current health problems, and this was true for over 80% of those with spina bifida.

Many of the cerebral palsied young people had clearly physically deteriorated since they left school and had become less mobile, and there were more fixed contractures. There was a marked absence of reassessment. Only a minority continued to receive physiotherapy although there was a definite need. One young man in the London sample could not transfer on to a toilet, although with therapy he could clearly have achieved this.

Growing Concern — continued

General medical care in many instances was inadequate and there were many cases of poor health monitoring. Several young people who were using drugs for epilepsy had a prescription that had not been reviewed in one case for as long as 15 years, and in others for at least 10 years. Many young people were also on valium, again for no very clear reason.

For young people with spina bifida, problems of obesity combined with a deteriorating spinal condition were particularly worrying and were probably contributing to an increase in respiratory problems. There were many occurrences of skin care problems, yet often these were not being treated.

Many had not had any advice from a consultant for some years. Two people were seen with unclosed primary lesions (myelomeningocele). One of these was leaking and infected, and there had been no direct medical contact for three years. *"In our view the majority of the young people seen would have benefitted from an experienced reappraisal by a competent team of health professionals"*.

About a quarter of the sample with spina bifida had epilepsy as a complication of their physical handicap. Not only were medications rarely reviewed, but as far as could be ascertained, none of the parents were given any advice on fit management.

Dental Treatment

Access to dental treatment is likely to become a problem after leaving the paediatric services. Parents said that 'high street' dentists were unwilling to tackle the problems of dental care for the handicapped and dental specialists were exceedingly rare. Very often a dental clinic for the handicapped was built up around an interested specialist and if he retired or moved on the clinic was likely to cease.

Speech Therapy

Evidence also suggested that after leaving school the availability of speech therapy decreases sharply.

"We have found a number of cases where inclusion on a speech therapy programme would be of considerable benefit, not just for the remediation of articulation problems, but also as a help with eating and swallowing difficulties".

The speech therapist on the team estimated that 55% of the young people seen had communication problems. Of these 90% would have benefitted from seeing a speech therapist, yet only about 10% were currently having speech therapy on any regular basis.

Sex Education

The Warnock Report (1978) found that sex education and counselling for the handicapped tended to be handled very poorly in schools. This is particularly unfortunate in view of the restricted social contact of handicapped teenagers. They have less opportunity of picking up information from alternative sources than their non-handicapped peers. While 78% had received sex education, for 90% of these the advice had not been geared towards someone with a handicap. For many the whole topic of sex was inadequately taught and was a source of frustration and embarrassment for them. There is a definite need for a specialist service. However, it might be that if a special clinic were set up it might not be used because of embarrassment and bashfulness. *"Rather I get the impression that this sort of counselling might be better integrated into say a clinic of a more multi-disciplinary nature where counselling comes as part of the total package of assessment and consultation"*.

Genetic Counselling

While many of the physical conditions seen by the team did not have a genetic link, 75% of the young people seen did not know whether their handicap was hereditary or not and were worried about future consequences. Some had been advised by their GPs, and on a couple of occasions by their consultant, but the majority remained ignorant about the consequences of their physical condition.

Psychological Problems

"It is generally accepted now that young people with handicaps experience at some point during adolescence, psychological problems at an elevated rate — somewhere around two to three times the rate of a normal school-child population, rising up to five times the rate for young people where there is associated brain damage. In studies of the handicapped adolescent, a prevalence of psychological problems of the order of 60-70% is not uncommon. These problems usually take the form of depression, low self-esteem, anxiety and inappropriate social behaviour, and they are often related to the severity of the handicapping condition and problems such as mobility difficulties or incontinence. Despite these elevated rates of psychological problems, less than 5% in our study were receiving the services of a counsellor or psychologist. . . "

Take up of Cash Benefits

While the take-up of the disability benefits was in general reasonable, the take-up of other benefits such as the income replacement benefits and supplementary benefit was very much poorer.

The Future

The study found that 72% of families with a son or daughter living with them at home could see problems looming in the future. There was a high level of dependancy on parents. Less than 20% of families were receiving any practical help in the home, and this was usually from friends and relatives and not from the statutory services. Many families felt they had been deserted by the statutory services, about 60% felt there had been no future plans made for the health care and education of their handicapped son or daughter.

Education

Over half the sample families felt that the education received had been undemanding and unstimulating. There were a number of cases where young people who were clearly at examination standard had not been given the facility to take exams at special school. They felt that school hadn't been geared up to the demands of post-school life and there was a lack of transition advice (about 44%).

Living Skills

A large proportion of the young people in the study felt that they had left school with far fewer skills than they required for living an independent or as near independent life as possible. Where independence training had been given this was usually much too near to leaving school and often described as inadequate.

Independence training usually focuses on practical skills such as washing and dressing, housework, cooking and so on. These are necessary skills, yet many had not reached their potential in this area of development.

Continued on next page

Social Skills

These include the ability to be able to interact confidently with other people, to be able to start up a conversation, give opinions, be able to go to social events, etc. The study suggested that the problems the young people had in social situations were often quite marked and there was a considerable need for a programme of social skills training.

"We are currently in the process of putting together a social skill assessment and training package for physically handicapped people. The study is only in its infancy but the intention is for us to assess the ability of a sample of young people with physical handicaps to interact with others, and where there are difficulties provide individual and group social skills training. We hope to be able to report more fully on it round the middle of next year (1987)".

Summary of general findings

1 After leaving school, young handicapped adults experience a rapid decline in receipt of health and social services.

2 They generally receive inadequate and fragmented medical and social care.

3 Reduced contact with health services results in inadequate health monitoring, and the receipt of drugs for epilepsy, or tranquillizers often goes unchecked for years.

4 Not only do the health services stop after leaving school, but the personal records of the young person are no longer held by a co-ordinating body such as the District Handicap Team. Therefore, the young people tend to get lost in the NHS administration.

5 Information and advice which should be at a premium at this transition stage is extremely difficult to obtain. 70% of study families were dissatisfied with the standard of information they had received concerning diagnosis, prognosis and the types of health care available.

6 There seem rarely to be any long term health care plans for the young person. Paediatricians face a daunting prospect when they look for an adult specialist to whom they can refer their handicapped teenage client.

Help from a social worker

The social worker might seem to be an ideal person to provide support and information.

However, many families found social workers unhelpful particularly because they were often uninformed about benefits, aids and adaptations, and they rarely understood the particular handicap. A high turnover of social workers meant there was rarely any continuity of social work support.

Why should these problems arise?

1 Poorly organised services and a lack of trained personnel.

2 Lack of co-ordination and communication between the health, education and social services (particularly true of the relationship between the health services and day centres). This results in imprecise details of the number and type of health and welfare needs of the handicapped people in the community and makes planning of services very difficult.

3 A paucity of information easily available for the handicapped person leading to a poor take-up of the available service.

4 A general lack of support from the statutory services after school leaving age.

Can the situation be improved?

As already mentioned the District Handicap Teams provide specialist services for mentally and physically handicapped young people nominally only up to school leaving age. There are also Community Mental Handicap Teams which were set up following the recommendations of the National Development Group, an advisory body set up by government, to look at the services then being offered to mentally handicapped people. Their 1977 pamphlet 'Mentally Handicapped Children; a Plan for Action' recommended the setting up of teams solely to serve mentally handicapped people offering 'a cradle to the grave' co-ordination and information service. There are about 140 of these teams within the NHS in England.

"So we are now in the position where we have one team — the District Handicap Team — concerned with young people of school age with any handicapping condition, and a second team — the Community Mental Handicap Team — whose concern for post-school services is only for those with mental handicaps.

"Somewhere along the line the physically handicapped and the multi-handicapped over-16 year olds have been missed out of the co-ordinating framework".

Handicapped adult teams

The research team suggests that there should be two handicap teams, one for all handicapped children — as currently provided by the District Handicap Team — and another for all handicapped adults.

"The present Mental Handicap Team, while retaining its present function in relation to the mentally handicapped could widen out to include the physically handicapped and come within the ambit of a new Handicapped Adult Team, serving all handicapped adults. By forming links between these two teams — the District Handicap Team and the proposed Handicapped Adult Team — the transition from paediatric to adult health care could be much less of a trauma than it currently is."

GPs would continue to provide primary care, but the new Handicapped Adult Team would provide a specialist advice and health care back-up service.

"As a starting point this new team should include a physician with broad based experience in the management of adolescent/adult handicap. In addition the team should be able to provide or have the resources of all the medical specialists as well as the psychological, paramedical and welfare services. Apart from routine medical assessment, the team should be able to offer advice and services for particular medical problems such as urinary incontinence, bowel management and pressure sores, as well as providing or referring for occupational therapy, speech therapy and physiotherapy and sexual and genetic counselling. Because the health and social aspects of handicap are inextricably linked, advice and assistance with social problems relating to housing, employment, mobility, finance, leisure and so on should also be available through this new team.

Liason with the client and this new co-ordinating team could be by those with the greatest contact, such as a teacher, health visitor, or perhaps better still, a resource worker — a social worker with specialist skills in disability, rather like an ASBAH fieldworker."

Handicap young adult clinics have already been set up such as the one in Newcastle, set up by Jean Robson (LINK, Jan/Feb 1981). It is organised on a monthly basis and has the regular services of an orthopaedic surgeon,

Continued on next page

Growing Concern—continued

physiotherapist, occupational therapist, a DRO and a representative from the local disability information service to advise on benefits, and housing, etc. Dr. Thomas was interested to hear about Sussex ASBAH's success in setting up and continuing a similar clinic in Sussex at Chailey Hospital.

"These types of local innovation I think are excellent, but are too few and far between, and of course, usually operated on a shoestring budget".

"We need a more formal policy in which new co-ordinating Handicapped Adult Teams are set up in all District Health Authorities, preferably as a result of a DHSS recommendation, as with the inception of the District Handicap Teams."

"I am very keen too on the notion of a resource worker, working in the community, acting as both a source of information and providing a support service whilst acting as a link with the district based co-ordinating team."

At present, a young handicapped person can be in contact with many professionals across the health, education and social services, yet still be unaware of many of the facilities available. There is a considerable need to provide services under one roof, or around a single table, to avoid the problems of poor co-ordination and communication.

The proposal for a new multi-agency Handicapped Adult Team is aimed at ensuring an effective transfer from the child to adult orientated services.

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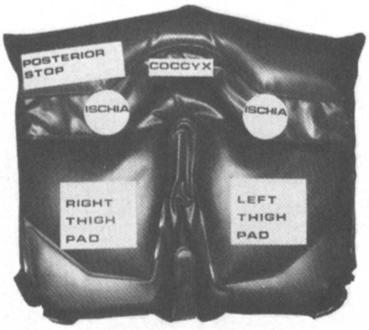

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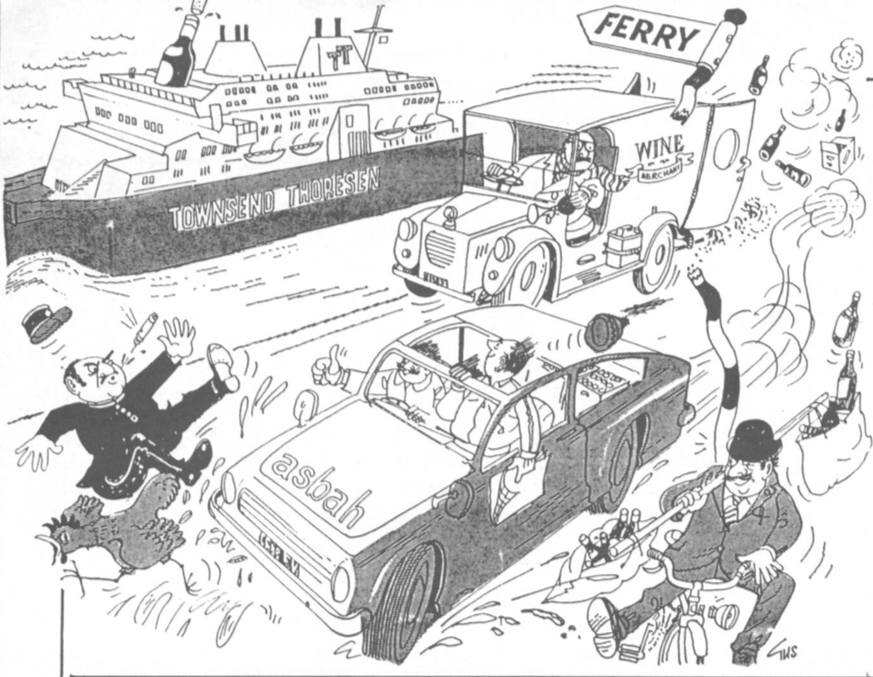


An annual event which centres on the race to bring Beaujolais Nouveau to Britain, and raises money for ASBAH.

The Beaujolais Challenge

CHEERS TO ALAN!

A personal account of the Beaujolais Rally by David Best who accompanied Alan Tomlinson, the first disabled driver to complete the route.

At a few moments past midnight on Wednesday November 19, outside the French village of Lacenas, 120 car engines burst into life and the vehicles surged forward out onto the open road.

The destination was Calais — and after that the Winter Gardens in Margate; in the boot of every car at least one case of Beaujolais Nouveau. The only other qualification for an entry in the Beaujolais Challenge organised by the British Automobile Racing Club (BARC), is to raise a minimum of £50 for ASBAH.

The aim of every car was to reach Calais in the shortest possible mileage but be in time to catch the 9.15 ferry to Dover. The emphasis was not on speed but competitors had to drive pretty swiftly to cover the 430 or so miles between Lacenas and Calais. Naturally crews were free to choose whatever route they liked. Rough farm tracks and unmade roads were all part of the fun!

The Beaujolais Run was not always organised in this way. It began in the late '60s as a sporting challenge between a handful of Englishmen who thought it 'a jolly jape' to see who could get the first bottles of New Beaujolais back to Britain after their "ceremonial" release for sale.

But man is a competitive beast by nature. What began as a social fun event became deadly serious, with more teams taking part every year. By the late '70s it was attracting what were virtually "works teams" with top British club racing drivers taking part.

It was clearly in danger of becoming an out-and-out road race and could have meant that sooner or later there was almost bound to be a tragic accident, or legislation would be brought in by the French authorities to ban it completely.

Not wanting to lose their annual frolic, the organisers began to dream up other ways of deciding the winner, with less emphasis on sheer performance. That was how the event came to be decided by the shortest route.

The challenge is great fun but having competed last year in appalling conditions with snow and ice I decided that a back seat was the order of the day in 1986. I needed a driver. Who did I know whose driving was as frantic as my own and who would enjoy a few days in France and a champagne breakfast in Margate?

I telephoned Alan Tomlinson who accepted without hesitation. I met Alan through work. I work for Ford Motor Company in an office which handles the supply of cars to disabled drivers through the Motability Scheme. Alan fits Alfred Bekker hand controls to cars for disabled drivers.

Alan, who lives in Cannock, Staffs is confined to a wheelchair after being paralysed in a rallying accident. The ca[illegible] which we used was an adapted 1.6 Esc[illegible] automatic transmission.

A spokesman for the BARC said: "This is the first time that a disabled person has completed the run and this achievement highlights the importance of mobility to disabled people and provides an inspiration to others".

The event was certainly inspiring and memorable. I don't actually remember much of the drive back as Alan was at the controls and I was asleep in the back of the car! I was struck by Alan's independence and, apart from being a little slower up and down stairs, there was nothing that I could do that Alan couldn't.

The event was a great success and most rewarding for both of us.

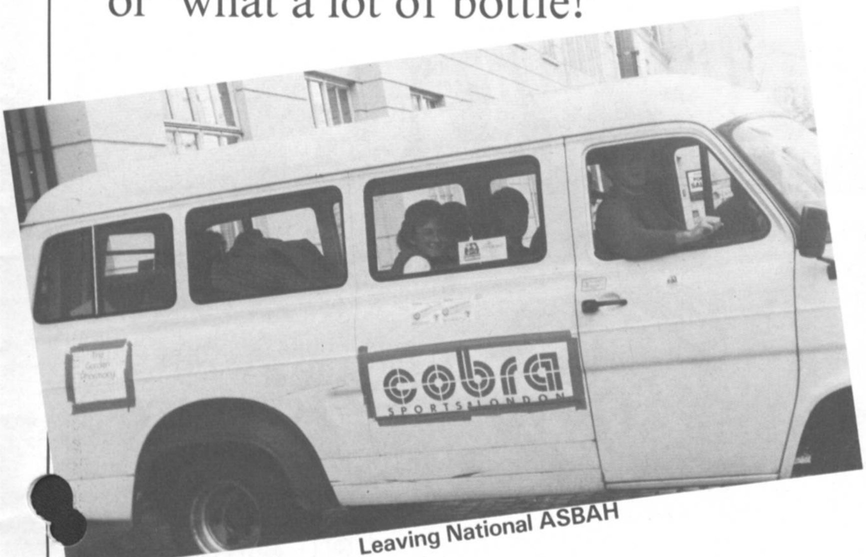
We came 24th overall beating an Audi Quattro, several Porche 928s an[illegible] BMWs. We came second in the Mot[illegible] Traders' class winning a set of engraved glasses. Most importantly we raised £2353.45 for ASBAH.

Bon santé! Alan Tomlinson (in the wheelchair) with David Best, standing behind and colleagues at Ford Motor Company who supported them on their Beaujolais run for ASBAH. See 'Cheers to Alan!'

THE BEAUJOLAIS RALLY WAS UNDERTAKEN BY A STRONG TEAM FROM LIFT (YOUNG ASBAH)

LIFT through France

or 'what a lot of bottle!'



Leaving National ASBAH

Outside the vineyard at Lacenas

Lisa and Chris Cain, Vicki Raymond, Karen Valk, Clare Michelmore (ASBAH's Disabled Living Adviser Co-ordinator), Andy Neale (LIFT Organiser), and Richard Poole (ASBAH's Beaujolais Challenge co-ordinator), made up the LIFT team for the Beaujolais Challenge — the first time LIFT had attempted it.

They set off in ASBAH's mini bus, and their entry was sponsored by very generous shopkeepers, restauranteurs and friends in London particularly in King's Cross, WC1, Southampton Row, Covent Garden, Camden Town and Drury Lane.

The journey passed without disaster. Vicki comments: "We intrepid travellers had no difficulty on the ferry, using all the facilities and the self-service cafe (thought it might have been different on high seas and with wide wheelchairs). The journey down was a mad-cap one, but fortunately the service stations are quite well set up for disabled people.

The team arrived safely at the hotel at Chatillon — Chevalier Norbert. They picked grapes at the vineyard, collected 13 cases of wine, and also had time to look round Chatillon before the return.

Vicki again: "The town was very old-world with little winding streets leading to bridges. We looked round the shops and found plenty of home-made chocolate shops. Wonderful!

Ready for the return journey

Enjoying the quaint town of Chatillon

LIFT WEEKEND 1987
July 31 — August 2
Owen's Park, Manchester University

Young people are invited to this sports/leisure weekend where there will be an opportunity to have a go at various activities (from beer making to self defence!). The cost will be about £40-45 all inclusive.

More details from the LIFT office at National ASBAH.

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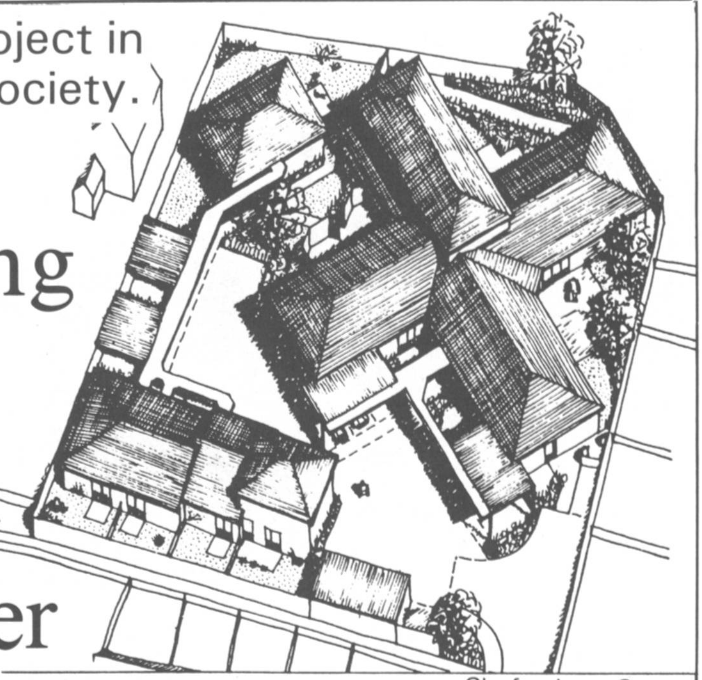
LINK has visited a new housing project in Wiltshire run by the Shaftesbury Society.

Building the future together



Shaftesbury Court

THE Shaftesbury Society's new housing project in Trowbridge, Wiltshire — Shaftesbury Court — is an example of a successful partnership between a voluntary organisation and the local authority.

In response to the need for this type of residential provision for the disabled, Wiltshire local authority has built Shaftesbury Court with Housing Corporation finance and then handed it over to the Shaftesbury Society to run and manage. The first residents moved in during the Spring of 1986.

There is general and in-depth interest from many authorities, churches, welfare teams and voluntary organisations in the residents and their needs, and this personal involvement has made [illegible]r a close working relationship to ensure [illegible]at each person is helped to be as independent as they wish.

The Shaftesbury Society was involved from the start with the planning and design of the Court. The result is a pleasing, comfortable and workable centre which, when full, will be home for 16 people.

The residents need to be reasonably able to cope with their own personal care, but the most important requirement is the right motivation. "We are looking for people who want to branch out independently and develop their own abilities" said David Wright, the Officer in charge.

When LINK visited in the Autumn there were still vacancies. There were nine residents; and a couple more who [illegible]ad been there for a short term 'trial [illegible]riod' were going to move in on a [illegible]rmanent basis.

Two of those already there have spina bifida. Mark Riley who is in his early thirties lived at home, but really wanted to try to make a go of it on his own. Mark is in a wheelchair and his great interest in life is weight lifting. He has travelled around the world taking part in international competitions with the British Sports Association for the Disabled. Mark lives in one of the three bungalows adjoining the main building.

Michael Farnell, 18, also has spina bifida but is able to walk. He lives in the main part of the Court and spends his days at Trowbridge Technical College on a work preparation course. Michael hopes to be able to find a job, and has the encouragement and help of Shaftesbury and local contacts.

Shaftesbury Court is situated in a residential area of Trowbridge, about a mile from the centre, but with good access to local shops and facilities. As the illustration shows, the main building is designed in the shape of a cross and the four 'arms' are self-contained wings each with four bedsits and its own kitchen and dining facilities. Each leads to the main lounge and recreational area and has access to the laundry room. Each resident pays through supplementary benefit taking into account individual allowances. (The fee is £191 weekly).

Jackie Gower, who with her husband Rick, act as Deputies to David Wright, explained that the care staff are there to help each resident to learn the various daily skills. Many of the residents are out during the day. Some go to a community centre in Trowbridge where the process of learning life skills is reinforced. Others are on training courses, and some are in work. Anyone who is in during the day is responsible for getting their own light lunch, with help as necessary, and then a main meal is cooked for everyone at 5.30 pm but eaten in the individual dining areas of each wing. A central dining room was turned down as this wouldn't have allowed privacy and would have smacked too much of the old-style residential home.

Getting his own lunch

Adjoining the main building are three bungalows for individuals or couples. Each resident is responsible for paying his or her own rent of £22 per week as well as rates and gas and electricity etc. There is also a magnificent family bungalow, (still empty when LINK visited), which with two bedrooms, a large lounge, fully fitted kitchen and a garden as some of the features, is wonderful value for a weekly rent of £29.60.

Each of the bedsits and the bungalows are on the Wolsey Care Call system which means that immediately help is always on hand.

Flexibility is the keynote at Shaftesbury Court. Attention has been paid to design features and fittings that can be changed according to the needs of each person — adjustable sinks and beds, different bathing facilities, simple working controls on washing machines.

There is also flexibility over the length of stay of each resident. For some Shaftesbury Court will be a long-term home. For others it will be an invaluable springboard to an even more independent life.

For more details get in touch with David Wright, Shaftesbury Court, Manor Close, Trowbridge, Wilts. Tel: Trowbridge 60228.

Caring

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Newslines NEWSLINES Newslines

- John Major — former Minister for Social Security — has been appointed as the new Minister for Disabled People. He succeeds Tony Newton.

Mr John Lee has been appointed Parliamentary Under Secretary of State for Employment. His responsibilities include equal opportunities and disabled people's employment issues.

- HALO — the Housing Association Liaison Office — has set up a pilot project to link disabled people who are seeking appropriate housing with Housing Associations that are looking for tenants of specially designed or adapted housing in London.

A register of disabled people is maintained from forms submitted by various referral agencies, and kept up to date. HALO will pass this information on to any Housing Association that has suitable property available. Being on the HALO register is not in itself an application for housing and other possibilities of obtaining accommodation should continue to be pursued.

Organisations can obtain a pack of registration forms and details from: Madeleine Foster, HALO, 189A Old Brompton Road, London SW5 0AR. Tel: 01 370 6591.

- Car controls which respond to spoken commands have been designed by a French company, Ets Kempf, and can be fitted to a standard car at the cost of about £3,000. A Ford Escort fitted with the controls was on show at the Birmingham Motor Show. Ford say that it could be useful for disabled people who have limited strength or reach, or cannot cope with complex hand controls. The system can be programmed to control most secondary functions such as radio and windscreen washers.

- A new workshop has opened in Ilford Essex making comfortable and fashionable clothes for disabled people. It is run by Redbridge Community Care Managing Agency.

Individual needs are catered for, and there is no labour charge. You only pay for material, threads etc, and you can choose your own materials or provide your own. (The quote for a pair of fitted trousers for a 9 year old was £6.50). All it takes is a visit for measuring.

The workshop is very near to Seven Kings Station.

For more details contact: Valerie Ralph, 627 High Road, Seven Kings, Ilford, Essex. Tel: 01 597 8065.

This project workshop also makes toys for handicapped children. Ideas for new toys are welcomed.

CLAIR WRIGHT, 10, an enthusiastic member of the Great Ayton and District Riding for the Disabled Group wearing a very special riding hat.

Clair who has hydrocephalus was unable to wear any of the commercially made hats as they were the wrong shape and too small. Like many other riders in her position she 'made do' for a year or two — using an orthopaedic helmet which didn't look good and was uncomfortable.

After some research the Group's Chairman, Mrs Jose Kelly, contacted a hat maker in London — Sid Patey — who took great interest and agreed to help.

After two visits for fittings, Pateys, produced a hat which not only looks good but feels good too. It was specially designed to fit Clair's head and therefore cost a good deal more than an off-the-peg model. It cost nearly £100 (including VAT) but the RDA group agreed to raise funds to help pay for the hat, and another RDA group — Yorkshire and Cleveland — helped with Clair's travelling costs from the North East to London for fittings.

Mrs Kelly said that Pateys could make a special riding hat mould for hydrocephalics which could be slightly adapted for each person if there was sufficient demand and this would bring down the cost.

For more details contact: Sid Patey (London) Ltd., Amelia Street, London SE17.

Photo: Courtesy of the RDA Newsletter.

- A recent survey undertaken by Liverpool Association for the Disabled found that 60% of disabled people and their families were not claiming their full entitlement to social security benefits. The research claimed that on average people were underclaiming by £20 per week. The Liverpool Association has now launched a city wide 'take-up campaign' to encourage disabled people to claim their social security benefits in full.

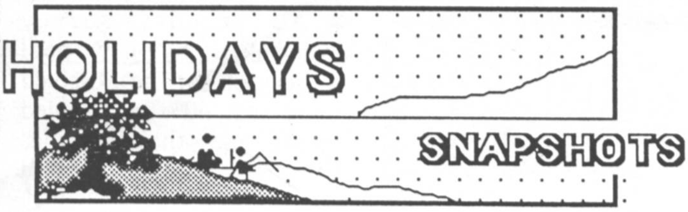
- THE OPEN University and Disabled Persons International are setting up a research centre run by and for disabled people. The aim is to encourage and support research by the disabled into topics that they themselves feel to be of importance, and particularly into their difficulties in relating to a world designed for the able-bodied.

Edis Bevan, the Centre's research assistant, hopes that research will be directed towards social inventions as opposed to "technical fixes through hardware aids. Disabled people too often live in information ghettoes," says Bevan "It is important that patterns of information exchange be built up to break the walls of the ghettoes."

The Centre wants information on existing research by disabled people and organisations for its database. DPI Research Centre, Gardner Building, OU, Walton Hall, Milton Keynes MK7 6AA.

- A Code of Practice governing the conduct of wheelchair distributors has been drawn up by BAWD (The British Association of Wheelchair Distributors). It seeks to ensure that the powered or manual wheelchair purchased is suitable for the purchaser's needs, that 'reasonable and fair tuition' in the use of the vehicle is given, that an 'efficient and swift' repair service is offered, and that complaints are handled seriously and promptly.

BAWD is at Ashley Mobility, Hay Road, Hay Mills, Birmingham B25 8HY



HOLIDAYS SNAPSHOTS

Winged Fellowship is running a number of SPECIAL INTEREST FORTNIGHTS during 1987: Fishing, Music, Drama, and Craft are the main subjects, and there are also fortnights for Youth (16-30s) and another for 30-45 year olds.

The Winged Fellowship Holiday centres are Cabhill House, Redhill, Surrey; Jubilee Lodge, Chigwell, Essex; and Skylarks at West Bridgford in Nottinghamshire.

The Fellowship welcomes any disabled person over the age of 16 for a holiday at any time (not just for the Special Interest Fortnights) and also arranges overseas holidays for small groups.

Details from: Winged Fellowship, Angel House, Pentonville Road, London N1 9DX. Tel: 01 833 2594.

'Myfanwy' is the name of a specially built CANAL BOAT owned by the Vale of Llangollen Canal Boat Trust to meet the needs of disabled people for day trips or holidays. Any group, family or individual can book. The boat accommodates up to 12, including helpers, for day and half day trips, or up to six people, including helpers, for cruises. The Trust makes no charge for the use of 'Myfanwy'. It costs £60 a day to operate the boat and contributions towards this cost are welcome.

Further details from: Vale of Llangollen Canal Boat Trust, East Street, Llangollen, Clwyd. Tel: 0978 861450.

Upper Lough Erne in Northern Ireland is the setting for an ACTIVITY CENTRE which provides courses, holidays and activities for disabled and able-bodied people. It is run by a charity SHARE. Activities such as sailing, fishing, canoeing, orienteering, camping, birdwatching and crafts are available. (In winter SHARE offers inexpensive accommodation on a self-catering basis for groups or individuals for only £6 per person per weekend).

Details from: The SHARE Centre, Smiths Strand, Lisnaskea, Co. Fermanagh, Northern Ireland. Tel: 036 57 22122.

"Indian Chief" is a 55 foot NARROWBOAT, purpose built this year, with toilet and central heating. It is fitted with a ramp and wheelchair lift, and its fold-down seating makes ample room for wheelchairs. All the listed trips start from Stoke Bruerne, Northamptonshire, but different starting points can be arranged. The boat operates for 12 months of the year.

Further details from: The Boat Inn, Stoke Bruerne, Nr Towcester, Northants. Tel: (0604) 862428.

Two specially designed narrowboats are available for hire on canals in the Midlands and in Wales. Both narrowboats can be operated from a wheelchair and are equipped with full washing and cooking facilities, hydraulic lifts, and ship-to-shore ramps. Kingfisher I (sleeps 7 people) and operates from Rugby in the Midlands; Kingfisher II sleeps five and operates from the Llangollen Canal in Wales.

Details from the Spinal Injuries Association, Yeoman House, 76 St. James's Lane, London N10 3DF. Tel: 01 444 2121.

The Scottish Association has two adapted cottages and four adapted caravans for self-catering holidays which it will be pleased to rent out to individuals or families. The Association will be pleased to answer general holiday enquiries. It has given below two or three suggestions for holidays in Scotland:

The Trefoil Centre near Edinburgh is a converted country house with a swimming pool, spacious grounds and is fully adapted. Open all the year and suitable for individuals, families or groups. *Apply: The Trefoil Centre, Gogarbank, Edinburgh. Tel: 031 339 3148.*

Stewart Hall is a purpose-built student hall of residence for disabled students and is available during the holidays. Full board is provided. *Apply: The Principal, Motherwell College of Further Education, Motherwell, Lanarkshire, Scotland.*

An adapted flat for self-catering holidays is available in Edinburgh through *The Thistle Foundation, Niddrie, Mains Road, Edinburgh. Tel: 031 661 3366.*

Children and adults with physical disabilities are invited to register for summer adventures at Camp Courage and Courage North in Minnesota, USA. Camp Courage is near Maple Lake, and Courage North on Lake George in the north of Minnesota. They offer accessible facilities, lakes and woods and a wide variety of camp activities such as crafts and nature study to video photography, swimming, sports, riding etc.

Details from: Camping Department, Courage Center, 3915 Golden Valley Road, Golden Valley, Minnesota 55422.

In Savona, Ligure, Italy there is a youth hostel with full facilities for disabled people. It is in the countryside, 4 km from the sea. The fees are L.7000 for bed and breakfast, and L.6500 for dinner and lunch or a packed lunch. Parties of disabled young people would be welcome. The hostel is open from the end of March until the end of September.

Details from: Co-op 'Punto Verde', Ostello per la Gioventù, 'Cesare de Franceschini', Via alla Strà 29, 17100 Savona, Italy.

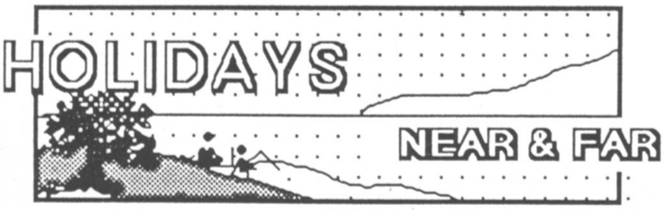
New horizons will be opened up for hundreds of physically handicapped people in the spring when the Jubilee Sailing Trust's new £2.5m. square-rigged barque *Lord Nelson* begins her first full season of voyages with disabled adventurers comprising half the crew on every trip.

The largest sailing vessel under a British flag to have been built in Britain for over 75 years — and the only one in the world to have been specifically designed to accommodate the needs of the disabled — she provides the able-bodied and disabled with the opportunity to enjoy a new type of adventure holiday and with a challenge to their abilities which usually results in a new-found sense of achievement.

The 400 ton, three-masted, steel-hulled ship, 171 ft long, carries a 42-strong voyage crew of whom 21 are physically handicapped including up to eight in wheelchairs, and all are expected to play as full a part as possible in the sailing of the vessel and in the everyday chores. In addition there are a professional captain and sailing master and six other permanent crew, including a nurse.

A full programme of voyages ranging from a weekend to a fortnight out of various ports around the British coast has been arranged for the season, and berths are available to both able-bodied and disabled people of either sex, and aged 16-70.

Details from: Jubilee Sailing Trust, Atlantic Road, Eastern Docks, Southampton SO1 1GD.



HOLIDAYS NEAR & FAR

IN recent years there has been a great upsurge in holidays for disabled people, and facilities available in all parts of the world. Keeping up with all the information has been difficult, but Mobility International has been doing its best. It has amassed a great deal of information about holidays overseas, and is happy to answer enquiries about different countries. During 1987 it is hoping to computerise all the information, but meanwhile can still help enquirers.

Mobility International offers young people (aged about 18-30) able-bodied and disabled, many opportunities to meet together and share experiences. Below is part of their 1987 programme.

Annual General Meeting, May 8 – 10. Thessaloniki, Greece. (In English and Greek).

As well as the business side of the meeting, there will be sessions on independent living, co-operatives, mainstreaming, and working methods/communication. Mobility International is also organising sightseeing and tourist facilities suitable for those in wheelchairs, before and/or after the conference for young people who would like to combine the meeting with a holiday.
Ref: EC–5–87. Closing Date: March 15

Ecology and Environmental Awareness. June. Denmark (In English).

This will appeal to disabled and able-bodied young people interested in nature, the environment and conservation. The course will be at beginner's level. There will be a 'nature' excursion each day and plenty of time for fun too. It is being organised in collaboration with Youth and Environmental Europe.
Ref: EC–12–87. Closing Date February 28

Women and Handicap. Early Summer. Nijmegen, Netherlands (In English).

The first 'Women and Handicap' seminar was held last year and was such a success, that this is a follow-up by popular demand. The emphasis will be on those who are 'disabled' rather than generally 'handicapped'. Topics for discussion may include leisure, work places, relationships and sexuality, and genetic engineering. This is a unique opportunity for European women with disabilities to exchange experiences discuss problems and enjoy themselves.
Ref: EC–6–87. Closing Date March 31

Bicycle Power, Early July, Drenthe, Netherlands (In Dutch and English).

Het Timmerholt is an attractive, fully accessible centre in Drenthe which each year has an invasion of about 500 cyclists many of them with disabilities. There are 400 kms of special paths for this event. The cyclists tour the region each day, stopping off at different villages where a celebration is planned. Mobility International has been invited this year to give the programme an international element. There will be bicycles, tricycles and tandems, able-bodied and disabled cyclists.
Ref: EC–10–87. Closing Date May 1

English as a Foreign Language. August 14 – 30. Alton, England.

This is a language course for phsyically disabled students held at a special school for physically disabled students. The school's facilities include a gym and a swimming pool and all facilities are accessible. There will be five hours tuition daily, at three different levels, and also trips to London, Oxford and Brighton.
Ref: EC–2–87. Closing Date May 31

Self-catering holidays in Greece. August 15 – 22, 22 – 29

An accessible bungalow is available at a site 32 km from Athens, and not far from the sea. The bungalow will accommodate up to 30 people. Mobility International organises transport between Athens airport and the bungalow, plus one full day excursion each week. The rest is up to the group. Applications will be considered from individuals, or groups for one or two weeks.
Ref: GR–1–87. Closing Date March 31

Living Together. August 22 – 29, Stackpole, West Wales.

This is an opportunity for an international group of young people to share their lives for a week in a community of six cottages on the beautiful Welsh coast.
Ref: EC–7–87. Closing Date March 31

Catalan Cultural Week. September, Barcelona, Spain. (Spanish, French and English).

This will appeal to anyone with an interest in Catalan food, music, dance, language and architecture.
Ref: EC–4–87. Closing Date May 31.

The World Meets America IV, Orlando, Florida, USA. Early Nov (In English).

This is a straightforward, fun holiday with warm weather and lots of attractions — Disneyworld, EPCT, Sea World, etc.
Ref: USA–1–87. Closing Date June 1

Most of the projects are subsidised, and travel awards are available on some.

Full details from: Mobility International, 62 Union Street, London SE1 1TD. Tel: 01 403 5688.

Chance to visit New Zealand

A holiday in New Zealand — that's the aim of Mobility International for 1988 if there is sufficient interest. If you think you may be interested contact Suzy Beaumont at Mobility International (address below) as soon as you can.

Study tours to Russia and Greece

PROJECT PHOENIX TRUST arranges overseas study tours for the disabled and recruits all helpers, including two SRNs on each visit. This means that the tours are suitable for unaccompanied adults with handicaps.

The 1987 programme is:

Moscow — 7 days, April/-May. General interest and Soviet culture. Cost: £500 plus visa and insurance.

Athens — 10 days, September. Classical studies. Cost: £652 plus lunches and insurance.

Details: Mrs V Saunders, Secretary, Project Phoenix Trust, 68 Rochfords, Coffee Hall, Milton Keynes, MK6 5DJ.

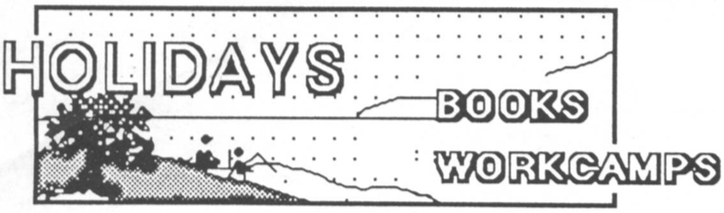
DON'T FORGET. . .

ASBAH has a great deal of information about all types of holidays, advice for travellers, insurance information, precautions to take etc.

ASBAH has a list of useful medical contacts abroad. So if you are holidaying outside Britain why not get in touch and go armed with the name and address of a helpful doctor, medical centre/hospital.

ASBAH runs its own range of holiday courses at Five Oaks, near Ilkley. . . from sporting activities to a computer course. The full list was in the last LINK (page 21). For full information contact Paul Cooper, Five Oaks, The Drive, Ben Rhydding, Nr Ilkley, West Yorkshire. Tel: 0943 603013

ASBAH is hosting a Learner Driver Course at the Stackpole Trust, Pembrokeshire, March 15–22. Details from Anne Monaghan at ASBAH.



Holidays for Disabled People
This hardy annual from RADAR cannot be equalled for information about all types of holidays. The 1987 edition is now available price £2 from branches of W.H.Smith.

Directory of Disabled People has a very useful section on holidays abroad. It lists different countries and gives the names of organisations and relevant publications for further information. Written by Ann Darnbrough and Derek Kinrade it is published in association with RADAR from where it can be obtained, price £12.50 to include P and P: 25 Mortimer Street, London W1N 8AB *(ASBAH has a copy and would be pleased to look up the relevant information about the country in which you are interested. Contact ASBAH and ask for Pat Corns).*

Mobility International can help you with enquiries about holidays in different countries. They are at present building up a database so that in time a great deal of information will be readily available on computer. But meanwhile they can still share their great wealth of knowledge! The address is 62 Union Street, London SE1 1TD. Tel: 01 403 5688. Anthony Lumley.

Ou Ferons Nous Etapes?
This is the 4th edition of the French Accommodation guide for disabled people. Price 70F from: APF, Delegation de Paris, 22 Rue du Pere Guerin, 75013 Paris, France.

Sweden is Terrific
The Swedish Tourist Board has produced a new holiday guide for disabled people. Available from: Sveriges Turisrad, Hamagartan 27, Box 7473, S-10392 Stockholm, Sweden. Tel: (46) 8-789-2000.

Physically Disabled Traveller's Guide.
It has information on facilities for disabled travellers on various airlines, details of the services offered by several dozen specialised travel agencies. Other information includes the accessibility guidelines of several large hotel chains, accessible campgrounds, summer camps, and wilderness expeditions. Price: $9.95 plus $2.00 postage from: Resource Directories, 3103 Parkway, Suite 212, Toledo, OH 43606, USA.

TCP Phrasebook and Guide to Holiday Health.
This is useful if you need medical attention whilst abroad. It contains medical phrases in French, Spanish, Italian and Greek, and there is a special section for disabled holidaymakers. Available on general sale at retail chemists in Great Britain.

How to Help the Disabled Traveller.
ABTA, in conjunction with the Holiday Care Service and RADAR, has produced the above leaflet primarily for commercial holiday companies, to help them help any of their clients who may be physically disabled. For further details contact: Ms Diana Hanks, Conciliation Manager, Consumer Relations Department, ABTA, 55-57 Newman Street, London W1P 4AH. Tel: 01-637 2444.

HOLIDAY HELPERS is a new scheme set up by the Holiday Care Service to find suitable helpers for people who cannot go on holiday on their own. The Holiday Care Service cannot pay any part of the cost of the helper's holiday but may be able to give advice on where financial assistance could be obtained.

Details from: Tim Smith, Holiday Helpers, 2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW. Tel: 0293 775137.

Everybody gains in international camps

INTERNATIONAL workcamps are a unique form of voluntary service for any young person over 18, whether or not they are disabled. The project benefits through the volunteers' work and the volunteers benefit through the experience of living and working as part of an international group.

They are run by SCI — Service Civil International. (IVS — International Voluntary Service — is the UK branch of SCI).

Camps last from one to four weeks and there is a wide variety of work projects. They all have one thing in common. The workcamp takes place because the project needs outside support, but the work is designed to help the project become independent of the need for such support.

For this reason, IVS and the workcamp sponsors try to involve local people in the planning, running and follow-up to workcamps and to create a strong relationship between them and the volunteers. The camp may make all the difference to the scale of what a community project ca[illegible] undertake, e.g. on playschemes or conservation work.

The volunteers become involved in discussions about the nature of the work they are doing and the reasons why it is needed. Indeed some camps have a formal element of study built into their programme to enable this to happen to a greater degree.

The volunteers form international teams of between six and eighteen people, often of very different backgrounds and experience. Living together and working as a team towards common objectives helps to break down barriers and results in a greater understanding of differences in culture and outlook. In this way, workcamps promote international understanding and are a positive and very practical step towards peace.

Workcamps can involve:

- **WORK WITH CHILDREN**
- **WORK WITH PEOPLE WITH DISABILITIES AND MENTAL HEALTH PROBLEMS**
- **MANUAL CAMPS**
- **WORK/STUDY CAMPS**
- **FAMILY CAMPS**

IVS welcome applications from volunteers with disabilities. Accommodation and other facilities can be checked when they apply and the choice of project is left to the volunteer according to what he/she judges appropriate to his/her needs and abilities.

Most of the camps take place during the summer from June to September. In the UK there are some during the autumn and spring. Occasionally there are Workcamps in Western Europe at Christmas and Easter.

All volunteers must be at least 18 years old and those wishing to go abroad must have previous Workcamp, or similar voluntary work experience.

Details of autumn Workcamps are available from mid Sept. winter Workcamps from late Oct. Details of Workcamps in the spring are available from late Feb. and for the summer from early May. Please write for details enclosing a large s.a.e. to National Office IVS, 53 Regent Rd, Leicester LE1 6YL. Tel: Leicester 541862.

Advertising

FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS
Rate: £3.00 for 30 words max; £4.25 for 30-45 words; £5.50 for 45-60 words. Cheque or postal order payable to 'ASBAH'.
Adverts for next LINK (March/April) should be in by February 15. Send to: The Editor, Mrs Sue Gearing, The Gables, Long Lane, Wrington, Avon, BS18 7NE. Tel: 0934 862279.

HOLIDAY ACCOMMODATION

HEYSHAM, Nr. Morecambe. Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 5 Roman Way, Whitchurch, Shropshire. Tel: Whitchurch 3691.

BORTH, Nr. Aberystwyth. 6-berth de luxe holiday home. Licensed site. Suitable for wheelchair users who live independently. Details: J. Carter, 1 Meadow Road, Craven Arms, Shropshire.

EXMOUTH Devon. Fully equipped, self-catering, 2-bedroom bungalow (sleeps 7). Full central heating. Details: Herts and S. Beds Association. J. Harper, 70 Grove Road, Harpenden, Herts. Tel: 05827 69213 (evenings).

CENARTH, W. Wales. Luxury chalet adapted for wheelchairs. Sleeps 6. Colour TV. Heated pool, restaurant, shop, launderette. Details: Mr T. Noon, 14 The Chase, Leicester LE3 2WA. Tel: 0533 895691.

WINTERTON-ON-SEA, Nr Great Yarmouth. Chalet-bungalow. Sleeps six. Fully equipped. Bathroom—toilet, Accessible for wheelchairs. TV. Shop. Take-away. Club room (live music). Children's play areas. Heated indoor pool. Details: Mr R. H. J. Morris. Tel: 0494 32184.

ISLE OF WIGHT. Very well equipped chalet with easy wheelchair access at **Brambles Chine, Freshwater.** Sleeps 6. Indoor heated pool, club, shop. Details: Ring or write: Mrs S. Gully, Old Princelett, Apse Heath, Sandown, Isle-of-Wight. Tel: 0983 863354.

RYE HARBOUR, Sussex. Fully equipped mobile home, adapted for wheelchair users. Sleeps 4. Clubhouse on site. Details: Mr P. Borthwick, 170 Hollington Old Lane, St Leonards, E. Sussex. Tel: 0424 51145.

SOUTH COAST. Very well equipped chalet with easy wheelchair access at **Romney Sands Holiday Village.** Sleeps 6. Many facilities including heated indoor swimming pools, large club house and entertainment. Very reasonable rates. Details: Ring or write to Mrs H. McLeod, 23 Harvest Ridge, Leybourne, nr. Maidstone, Kent. Tel: West Malling (0732) 840868.

SELSEY, Sussex. Purpose built 7-berth mobile home fully adapted for wheelchair users. Cot available. Licensed site. Details: Mrs M. Holmes, 11 Grove Rd., Ashtead, Surrey KT21 1BE. Tel: Ashtead (03722) 76730.

WESTWARD HO. North Devon. Holiday bungalow. Sleeps 6. Excellent club, swimming pool, shop on site. Near Sandy beach. SAE to: Mr G. L. Oakley, 12 Farleigh Rd., Perton, Wolverhampton. Tel: Wolv. 751484.

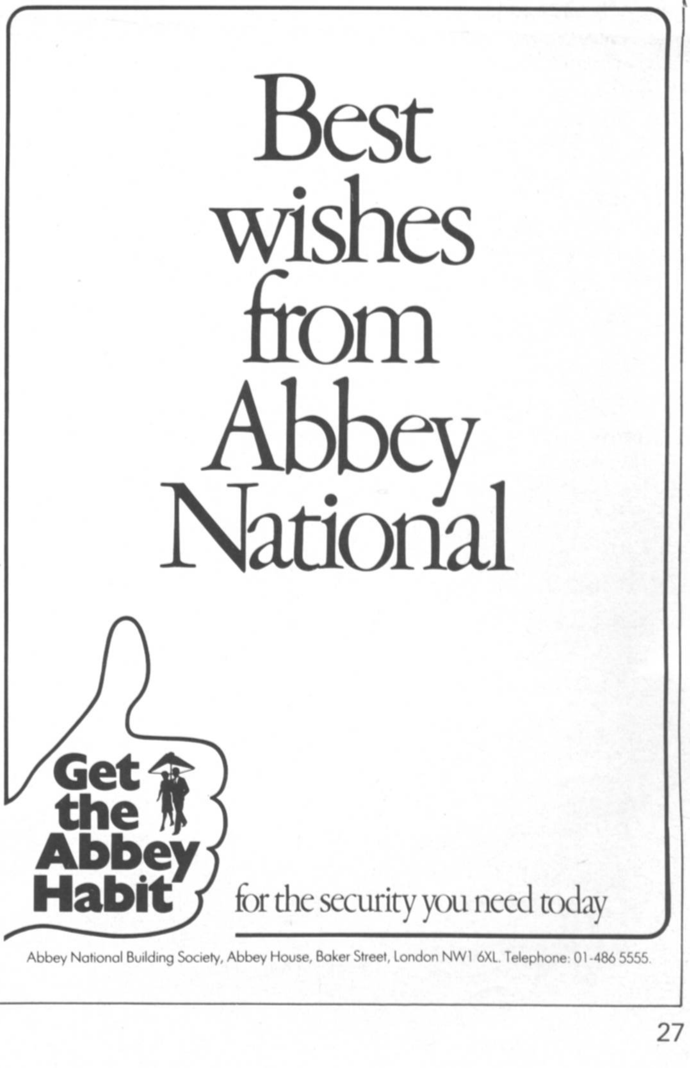
EXCHANGE & MART

Batricar red. 4 years old. Excellent condition with hood, lights and battery. £950 ONO. Tel: Halifax (0422) 205281.

BEC Horizon 40 electric wheelchair. Kerb climber. Hardly used. Was £1,143 new. For sale: £800 ONO. Tel: Mr Hargreave, Manchester (061) 436 2048 15 Podsmead Rd., Woodhouse Park, Manchester M22 6UZ.

Ford Escort 1.3, 1985. Ocean Blue, taxed 6 mnths. Fully equipped with hydraulically operated wheelchair which lifts into the front passenger seat space. Wheelchair suitable for indoor or outdoor use. 800 + miles. Price £6,500 ono. Tel: Bognor Regis (0243) 824842 eves., or weekends.

FUNDRAISING? FUNDRAISING?
Printed pens, diaries, balloons, badges, etc. Ideas galore in our brochures. Free sample and price lists from **Shaw Fundraisers, Freepost, Rochdale OL12 7BR. Tel: 0706 342636 (evenings/weekends).**



Directory
of local associations

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Mrs Marlene Haigh,
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9 Alwen Walk,
North Brickhill,
Beds. MK41 7AY

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CAMBRIDGESHIRE
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Shotton,
Deeside,
Tel: Deeside 811074.

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Wolverhampton,
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Tel: Wolverhampton 738 724.

ESSEX
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106 Thorp Hall Ave.,
Thorpe Bay,
Essex
SS1 3AS
Tel: 0702-584817.

GLOUCESTERSHIRE
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60 Monks Croft,
Cheltenham,
Gloucs. GL51 7TO
Tel: 0242 32287.

GRANTHAM
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Grantham, Lincs. NG31 7PZ.
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Harpenden,
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Coronation Road,
Salisbury SP2 9DA.

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Derbys, S18 6GW.
Tel: Dronfield 415523.

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35 Trenleigh Gardens, Trench,
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Tel: Telford 612542.

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6 Lumsden Ave, Shirley,
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Mrs J Davies,
8 Oakhill Avenue,
Stoke-on-Trent, ST4 5JN.
Tel: Stoke-on-Trent 45365

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Sunderland.
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Moorefield Annexe,
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Padgate,
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DT8 3EA.
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Whitchurch, Shropshire.

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Mrs Pat Stridgeon,
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Leigh, WN7 2LQ.
Tel: 0942 676091

WIRRAL
Mrs M Hudson
28 Stavordale Road,
Moreton, Wirral,
L56 9PR.
Tel: 051 678 4409.

WORCESTERSHIRE
Mrs G Doleman,
9 Pelham Road,
Droitwich, Worcs. WR9 8NT.
Tel: 0905 775862.

YORKSHIRE NORTH
Miss F M Seward,
45 The Paddock, York YO2 6AW.
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Mr John Dewhurst,
62 Edmonton Place,
Bispham,
Blackpool.

Beeston
Mrs S S Goodfellow,
5 Cyril Avenue, Beeston.

Cannock & Walsall
Mr Ken Hall,
17 Wallhouse Street,
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Tel: Cannock 4847.

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23 Hathern Close,
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East Anglia
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7 Ash Close, Downham Market,
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Tel: 0366 382200.

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10 Turpin Close,
Gainsborough, Lincs.
DN21 1PA

Isle of Wight
Mr D J S Sprake,
Springfield, Town Lane,
Chale Green, Ventnor, I.O.W.
Tel: Chale Green 234.

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Mr Tudor Smith,
Newlands Farm,
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Nether Kellet,
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Tel: 0524 732681.

Rochdale
Mrs Ann Lawton,
20 Spencer Street,
Chadderton, Oldham,
Lancs.
Tel: 061 652487.

Somerset
Miss June Roberts,
1 Ilford Court,
Wiltshire Close,
Taunton.

Teesside
Mr J Gray,
Marchesi Centre, Tollesby Road,
Middlesbrough, Teesside.

OTHER AFFILIATED ASSOCIATIONS

WALES

LLANELLI
Mrs Janice Thomas,
St Paul's Close,
Llanelli.
Tel: Llanelli 57512.

MID-WALES
Mrs J Carter,
1 Meadow Road,
Craven Arms,
Shropshire SY7 9QY.

NORTH WALES
Mrs E Boddy,
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Fford Orsedd, Llandudno,
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Mrs Brenda Sharp,
38 Redbrick Crescent,
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Tel: Barry 735714.

NORTHERN IRELAND

Mr J. Rippey,
Long Eaves,
24 Tulleywiggan Road,
Cookstown,
Co. Tyrone.
Tel: Cookstown 62290.

OTHER ASSOCIATIONS

SCOTTISH SPINA BIFIDA ASSOCIATION

Executive Officer:
Mrs Audrey Smith,
190 Queensferry Road,
Edinburgh EH4 2BW.
Tel: 031-332 0743.

IRISH ASSOCIATION

Mr Michael Neville,
Old Nangor Road,
Clondalkin,
Dublin 22.
Tel: Dublin 01-572326.

Please will all local Secretaries who want entries changed contact: Mrs Sue Gearing, LINK Editor at National Office: ASBAH, 22 Upper Woburn Place, London WC1H 0EP. Tel: 01-388 1382.

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