

Link

FEBRUARY 1991 NO 132

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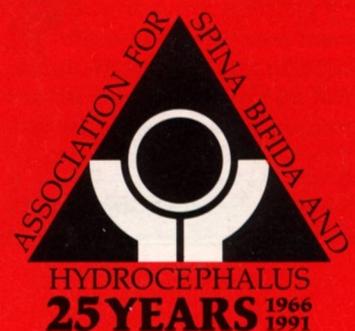
The magazine for people with
Spina Bifida and/or Hydrocephalus



IN THIS ISSUE

The needs of young people

Calendar competition



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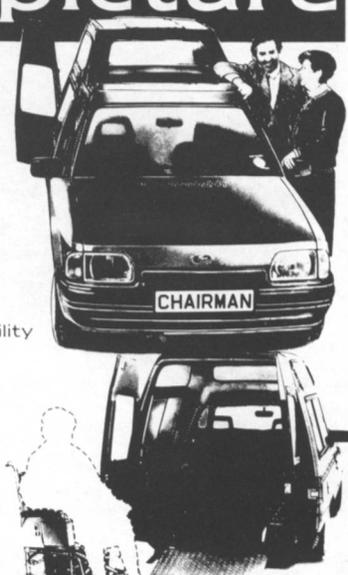
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The magazine for people with spina bifida and/or hydrocephalus

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Link

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THIS YEAR ASBAH will be reflecting on the past, as well as looking to the future, as we celebrate 25 years of the Association. LINK will be looking back at how ASBAH has changed over a quarter of a century, and looking forward to future developments as we enter a new era with our next executive director.

One of ASBAH's unique services to its clients which will continue to grow and improve is the mobility courses. In addition to a week long residential course for over 16s, weekend courses will be offered for school age children to attend with their parents. This will enable parents to encourage their children to use and extend the skills learnt when the family is back in the home environment.

Celebrations planned to mark ASBAH's Silver Jubilee have now been added to by Five Oaks, our residential training centre in Yorkshire, they will be holding a Cheese and Wine Evening on 6 July. For more details on this event contact them on 0943 609468.

Christmas Cards Offer

ASBAH is pulling out of the highly-competitive Christmas card selling business, and it will not publish a new brochure this year. The reason is that the low returns on the operation do not represent value for money.

The Association does, however, want to clear its existing stocks and is offering to sell these cards to local associations, any groups and individuals, at cost price. Please contact Penny Hebblewhite in the Appeals department for further information.



COVER - two of our Five Oaks residents get married, see page 7.
Photo: Telegraph & Argus, Bradford.

Can you help?

Dominique Cull, ASBAH's accommodation officer, has a client who is in need of a hoist for the bedroom. Do you have one which you no longer need?

If so, please contact Dominique at National Office.



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Miss Moyna P Gilbertson, MCSP, FBIM

Finance Director:

Mr Derek Knightbridge, FCCA

Assistant Director (Administration):

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Fieldwork Manager:

Mrs Teresa Cole, MICA

Disabled Living Service Manager:

Miss Rachel Stanworth, BA (Hons),
SRN, PGCE, MSc

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Mr Tony Britton

Research and Information Officer:

Miss Pat Corns, SRN

Regional Development Co-ordinator:

Mr Phillip Watson, BA (Hons), RGN

Five Oaks Centre Manager:

Miss Joan Pheasant, NNC

Appeals Manager:

Mr Roy Johnston

Obituary

MR TONY HUGHES, a former chairman of Wigan & Leigh ASBAH died at home on 20 January after a long illness.

Mr Hughes, whose daughter has spina bifida and hydrocephalus, had been involved first with the Wigan association and later the combined Wigan and Leigh association for over 20 years. He had also served as a member of the executive and on the council of ASBAH. Mary Roberts, present chairman of Wigan and Leigh said Mr Hughes was "an all rounder who had been involved in all aspects of the association's work and he will be sadly missed by us all."

New Executive Director for ASBAH

ASBAH's new executive director is to be Mr Andrew Russell, who will join us on 2 April as executive director-designate working alongside Miss Moyna Gilbertson until her retirement on 30 April after 15 years as executive director.

Mr Russell's current post is divisional general manager for MENCAP's eastern division which he set up in 1985 and he is responsible for an annual budget of £8million and a staff of 400.

A graduate of Fitzwilliam College, Cambridge, Mr Russell also trained at the Royal Agricultural College, Cirencester before spending some time as a farm manager.

Aged 41, he lives in Stamford, Lincolnshire, with his wife and twin children - a boy and girl.

Number of fieldworkers to double

The first stage in a scheme to double the number of ASBAH fieldworkers nationally has been launched in Cambridgeshire - the county in which National Office is situated. This follows the announcement of a major new initiative for funding an improved fieldwork service. Finance director Derek Knightbridge says the aim is to have "86 full-time fieldworkers, or the equivalent, in the next few years".

The expansion is to be funded by forms of business sponsorship, with firms pledging money over four years.

Deidre Pawsey and Donna Treanor, two members of the Appeals team, have been appointed as our first regional business executives and are

working with manager Roy Johnston to seek out companies who want to be part of the scheme. ASBAH is "mounting a three pronged attack on each county" to introduce the project:

- ◆ a media campaign
- ◆ mailing to targeted companies
- ◆ face to face presentations by our RBEs with prospective sponsors.

The average full cost of employing a full-time fieldworker for four years is £72,000. "This could be achieved by 18 companies pledging £1,000 a year for four years or any permutation thereof," said Mr Knightbridge. The extra sum needed to pay for the 86 fieldworkers will total £1.5 million a year at current prices.

Changing Roles

ASBAH's Hydrocephalus Support Group has a new co-ordinator. Rosemary Batchelor, previously one of our counsellors, joined the Disabled Living Services team in her new role in December, replacing Jane Williams who is now a full-time continence adviser on the DLS team.

Rosemary's post is for 17.5 hours per week, the rest of her week is spent teaching in special needs at Grantham College, Lincolnshire.

Northern Ireland

- *the next step forward*

A greatly improved fieldwork service for Northern Ireland should be up and running by April this year - the next step in ASBAH's regionalisation plans.

Interviews are taking place this month for those needed to boost the number of staff from the current three members to a quota of 15 for the new regional office. Seven part-time and two full-time fieldworkers, a regional co-ordinator, counsellor, one nursing and one therapist disabled living adviser, a half-time education co-ordinator and a secretary will make up the new team, based in Coleraine.

The co-ordinator for Northern Ireland is June Kerr, who was previously a fieldworker in the province. Before joining ASBAH June had been a teacher involved in special education for 15 years.

June sees her new post as a natural extension of her work for ASBAH, "Being the only full-time fieldworker in Northern Ireland I have often had to go into my colleagues' areas to provide cover and have become the 'contact' person with national office".

Northern Ireland was chosen to be the next 'region' because of "urgent need" says June, the current service is very stretched and she's excited by the prospect of having an opportunity for "more contact with professionals and closer contact with the regional hospital, where most of our referrals come from".

Marie McDonnell, who has been a part-time fieldworker in Fermanagh and parts of Tyrone will move to the DLS department as medical/continence adviser.

Funding for the regionalisation of the Northern Ireland service has been made possible because of the higher than expected increase in legacy income.



A prosperous start to the new year

ASBAH's new year got off to a good start with the presentation of a £500 cheque from Fiat Motor Sales. Their car dealership in West London won an award from Fiat for its showroom display but, as soon as they found out they'd won, the staff decided to donate the money to charity and picked on ASBAH as an ideal choice.

On receiving the donation Miss Moyna Gilbertson said "This is the fourth year that ASBAH has benefited from Fiat Motor Sales kindness. This latest gift is much appreciated and, once again, it will help ASBAH to help others."

Fundraising Cumbrians

ASBAH clients in Cumbria will benefit from the fundraising efforts of both a local mum, Mrs Annette Downie, and fieldworker Moira Foggo's local pub.

Mrs Downie, who has twins with hydrocephalus, is secretary of the Lakeland Terrier Club. The club asked her to nominate a charity for a £100 donation and she put ASBAH's name forward. Coupled with her personal fundraising efforts - a sponsored bike ride - she has been able to pass on a total of £436.

Meanwhile, at Moira's local, The Museum Inn, games of darts, dominoes and a tombola have further swelled the Cumbrian coffers by £250.



Vitamins and neural tube defects

Over the past two years, four studies to see whether extra vitamins prevent neural tube defects have published their results in medical journals - three in America and one in Australia. However, the results of these studies have not resolved the question.

The Medical Research Council began its vitamin study in 1983, in which ASBAH is involved, and it is probably the only study in progress in the world that is large enough and is sufficiently scientifically sound to be able to resolve the issue.

There are now 30 participating centres in seven different countries. Over 1700 women have been recruited to the study and more than 1100 women have completed their pregnancies. The aim is to collect information on 2000 pregnancies. At the current rate of recruitment this will take about another three years and it

is expected that women will be invited to join the study until February 1994. The study is monitored regularly by an independent committee and would be stopped or altered if a clear result was shown sooner.

If you would like details about who to contact regarding joining the study please write to:

Karen Fordham, Deputy MRC Vitamin Study Administrator, Environmental and Preventive Medicine, The Medical College of St Bartholomew's Hospital, Charter House Square, London EC1M 6BQ.

The Colin Graver Trust

A moving television documentary film has led to the formation of a new trust fund. The programme entitled 'A view from the bridge' was shown in the BBC's '40 Minutes' series. It charted the short life of Colin Graver, a 17-year old boy with speech and learning difficulties whose special needs had never been understood or adequately met. He committed suicide by jumping from Westminster Bridge. The producer believes the film illustrated the "sense of isolation and hopelessness which can face young people with special needs as they try to make something of their lives and raised questions about the education, training and employment of young people all over the country."

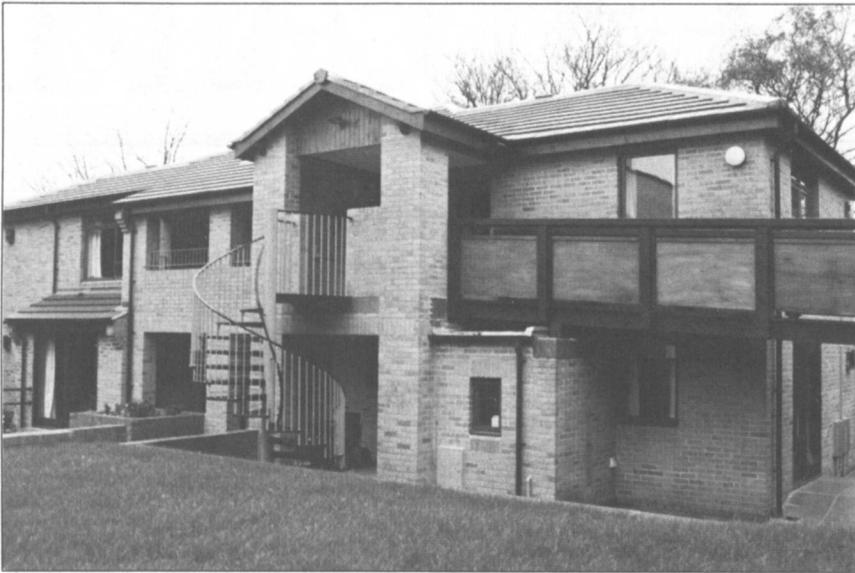
The Trust is setting up an award scheme for new ideas which will help youngsters with special needs to get the best from their schools, communities and jobs. Each year the individual or group which proposes the best initiative in special needs education, training or employment will be given a grant to try out their idea, which should take account of the opportunities presented by current technology. For further details of how to apply for an award or on the Trust itself write to Mr and Mrs Graver, c/o Room 2069, BBC Television, Kensington House, Richmond Way, London W14 0AX.

Man's best friend

'Assistance Dogs for Disabled People' is a new charity which aims to provide highly trained dogs to people with disabilities to provide companionship and improved quality of life as well as increased independence. The dogs will be able to perform simple tasks such as fetching 'named' articles, pressing switches etc.

For further information contact: The Grayling Company, 4 Bedford Square, London WC1B 3RA, telephone 071 255 2424.

Flat Share vacancy



Wharfedale, Five Oaks

THERE IS A VACANCY in the three-person, shared flat at Wharfedale, which is part of the Five Oaks complex, at Ilkley, Yorkshire.

The units consist of four flats which are suited to those able to live independently but needing some support in budgeting and other day-to-day living skills.

An alarm system, connected to Five Oaks, has been installed in case of emergencies. Each tenant is given an assured tenancy.

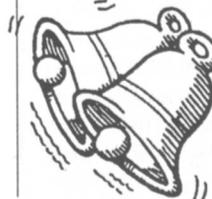
Anyone with spina bifida and/or hydrocephalus who is interested in the accommodation should contact the project worker, Helen Charlton on 0943 601550 or Joan Pheasant at Five Oaks on 0943 609468.

Wedding Bells at Five Oaks



Featured on our cover this month are Anita and Robert Murphy who married in January. The happy couple are both Five Oaks residents - they met at the centre when Robert moved there about 15 months ago. They soon got talking and discovered they had a common interest in football but, Anita told us, "We held very different views on which team to support - I'm a Leeds supporter and Robert's team is Liverpool". This shouldn't cause too much conflict for the newly-weds though as Anita has decided to come round to Robert's way of thinking, after all the couple will be making Liverpool their home town in the near future when their purpose built flat is ready to move into.

The ceremony took place in Bradford, where Anita lived before moving to Five Oaks. The bride wore a peach dress, with lace bodice and sleeves, which she made herself. The reception was held at Five Oaks and many



of the couple's friends from the area attended. We wish them every happiness in their new life together.

Triumph for ASBAH

MEMBERS of the Triumph Owners Motorcycle Club in Derbyshire lived up to their name by raising £550 for ASBAH through their sponsored 24-hour pool-playing marathon. Every year the club chooses a charity to benefit from its fundraising efforts and this year the proceeds will go to help ASBAH's clients in the Derbyshire area. The club's secretary - Diane Shilling - has a 10-year old son with hydrocephalus.



Pictured right - members of the club present the cheque to disabled living adviser Mary White (formerly fieldworker in the area). Photo courtesy Derby Evening Telegraph.



Maddie Blackburn is a research health visitor and is married with two children. Prior to working for ASBAH, she was employed as the child protection training co-ordinator for Greenwich Health Authority and as Education Officer to the mother and baby unit HMP Holloway.

She is currently working for Dr Martin Bax who is Senior Research Fellow within the Community Paediatric Research Unit, Westminster Children's Hospital, on the ASBAH research project 'The Health and Social Needs of Young Adults with Spina Bifida and Hydrocephalus'. She has been working part time on the project since April 1989 and on 1 April 1991 will begin a three year ASBAH research fellowship. This time will be used to complete the Health and Social Needs project and the additional research arising out of this study 'Sexuality and sexual knowledge in young adults with spina bifida and hydrocephalus aged 16 to 25 years'. In addition she will be producing, in conjunction with ASBAH, educational training materials on issues related to sexuality and disability arising from the study, and it is anticipated that she will be involved in other research projects, possibly with a greater emphasis on the problems arising from hydrocephalus, as well as completing her Master of Science degree.

Her professional interests also include Soviet Health Care and she recently visited a research centre in Moscow for children with Spina Bifida and Cerebral Palsy.

ASBAH

Maddie Blackburn reports on the study into health and social needs of young people with spina bifida and/or hydrocephalus

OVER the past two decades ASBAH have financed a number of research studies concerned with the needs of children with spina bifida and/or hydrocephalus and the development and provision of services. Most of the published research has

focused on the problems of these children in terms of their educational achievement, social and psychological development, personal care and attainment of independence. Much work has also been carried out on the various aspects of the child's medical condition but, paradoxically, for older children and young people over the age of 16 years very little research has been reported about their social and medical conditions until relatively recently. This may reflect the fact that intensive treatments of spina bifida and/or hydrocephalus only began in the early 1960s and it is only recently that relatively large numbers of people with this condition have survived into adulthood.

Two of the research projects currently being funded by ASBAH are: the one being carried out by Dr Bax, from the Community Paediatric Research Unit, Westminster Children's Hospital and the other a Body Image and Self Concept study headed by Peter Appleton, Chief Clinical Psychologist of Clywd Health Authority.

Dr Martin Bax, Senior Research Fellow and Chairman of ASBAH's medical executive committee, together with Dr Andrew Thomas and Dr Diane

Smythe, carried out a research project in the mid 1980s examining and assessing the health and social needs of a group of young disabled adults living in the north west Thames region of London and High Wycombe in Buckinghamshire. A small group of young adults with spina bifida and/or hydrocephalus were included in this study and the findings indicated a dearth of educational and career opportunities as well as a decline in contact with health and social services departments for these people once they left the education system. The findings of this study have now been published by the MacKeith press in a comprehensive text: 'The Health and Social Needs of Young Disabled Adults' (1989). This study received financial support from ASBAH and the Spastics Society.

In 1988 ASBAH invited Dr Bax to conduct a more in-depth study specifically investigating the health and social needs of young people living in a wider geographical area with spina bifida and/or hydrocephalus. I was invited to help him, initially for a two-year part-time period. As a health visitor, I have had considerable experience of working with young adults and

RESEARCH

families with special needs.

Within the north west Thames area of London where the major part of Dr Bax's study is being carried out there is a low incidence of spina bifida (0.31). From our initial investigation it was thought there were about 164 young adults with spina bifida and/or hydrocephalus living in the region. One hundred adults have been successfully located from various sources, hospital records, social service departments, the Family Fund in York and ASBAH. Permission was obtained from all ethics committees concerned and the young people were sent an explanatory letter outlining the purpose of the study and asking if they would be willing to participate. Where necessary a preliminary visit was made to the young person's home to offer a more detailed explanation to them, their parents or carers. Written consent was obtained prior to interviewing and medical assessment.

By the end of the study it is hoped that 70 to 80 young adults will have participated in an interview and medical assessment within their own home, hospital or venue suggested by the client. Sixteen young people living in Kent and Surrey have taken part in some trial, (pilot) and more in-depth interviews to provide some geographical and socio-economic comparisons.

The early studies from our research unit indicate that the outcome for the young physically disabled adult is often poor. Social situations often cause difficulties and the management of long-term health care, both by the individual and under

supervision is often unsatisfactory.

A social health interview was designed with the help of an epidemiologist and Dr Andrew Thomas, formerly research fellow within the research unit. I am conducting the interviews which include questions on education, career opportunities, mobility, independence training/living, health status, social life, self image and interpersonal relationships. To date over fifty interviews have been completed and each interview has lasted on average about two hours. During the interview, parent/carers are also invited to complete a questionnaire, as well as asking about the effects of the young person's disability on family life it also provides some check on the reliability of the young person's memory. Over 88% of our participants have hydrocephalus which appears to affect the ability to recall and absorb information.

A medical interview/assessment is being carried out following the social questionnaire. Information from this so far indicates that young people receive well supervised care until the age of sixteen years. In the north west Thames region, many of the young adults have received treatment since birth at Westminster Children's hospital. For many this often necessitates a two to three hour journey to attend out-patient clinics, followed by a very long wait and only then perhaps seeing a doctor for a few minutes or so. Until this year there was considerable difficulty in transferring patients to clinics which could deal adequately with the problems of adults with spina bifida and/or hydrocephalus. However, the

parents and young people themselves often resist transfer to adult medical centres as years of treatment establish a trust and bond between the paediatric staff and family. This has resulted in a situation where often patients of twenty-five years of age and older are still being admitted to an adolescent unit often more suited to treat considerably younger patients.

Many of course have attended special schools and colleges where they received help from doctors, nurses and therapists concerning their health needs. There is, alas, already evidence that the health of these young people deteriorates after leaving.

In 1990 ASBAH established a psychosexual counselling service under the direction of Mrs Pat Edser, national training co-ordinator for this service. The need for sex education and information has increased greatly over the last few years. In addition to the counselling service, ASBAH also provide training courses aimed at professionals, parents and carers. In the early 1980s ASBAH produced a Sex Education Handbook. The second edition, which included input from the Spastics Society, now requires revision. It is thought that leaflets and videos may be a preferred way of providing this information.

Our current research project has also indicated that sex education information is often inappropriate and ASBAH invited us to conduct a separate study, specifically looking at the sexuality and sexual knowledge of young adults with spina bifida and/or hydrocephalus aged sixteen to twenty-five years. The

➔ project dealing with health and social needs has temporarily been put in abeyance until the sexuality study has been completed.

Research relating to sex education provision in schools and colleges, as well as information about the physical and emotional needs of the disabled young adult, is limited. Current reports largely describe sexual activity and malfunction following traumatic or acquired injuries to the spinal cord. Disability inevitably has some impact on sexuality and immobility and may be of great concern to the disabled person, causing problems about self image and attractiveness to the opposite sex. Physically disabled people sometimes feel isolated and lonely and may have limited opportunities to share an emotional, physical or sexual relationship with their peers.

The sexuality study which is being carried out in the north west Thames and Kent districts hopes to provide some evaluation and recommendations for the future of the psychosexual counselling/training service; to obtain information about young adults' current knowledge of the anatomy and physiology of adolescence; to elucidate the type of sex education (if any) received in school or college or from other sources. The study also hopes to identify young people who require initial or additional sex education teaching or information and to explore the most efficient methods of delivering this information. This may be through formal teaching, videos, personal counselling etc. One hundred young adults with spina bifida and/or hydrocephalus, as well as a group of 100 healthy students of a similar age, have agreed to be interviewed to provide some comparative information. To date about 110 of the young adults have been interviewed.

On completion of this study, the community paediatric research unit will make some educational

training material, suitable for young adults and others involved in supporting and teaching about sexuality to young adults with spina bifida and/or hydrocephalus.

Interviews last about an hour and are carried out by me, usually at home or college, using a specially designed interview schedule. Pat Edser was also involved in some of the earlier interviews. So far, we have found that current sex education teaching is often inappropriate to the needs of this particular group of people as the presence of hydrocephalus inevitably has some impact on retaining knowledge. The study clearly indicates appropriate reinforcement teaching methods are necessary. Many of the young people interviewed can recall hearing specific terms and words, but have difficulty in explaining what they mean. Videos appear to be more popular than leaflets, textbooks and magazines. Many of the young adults say that they can review information on videos for short intervals regularly in the hope of remembering some of the key points.

Such interviews understandably generate feelings and thoughts in young adults which require skilled explanation and counselling. The interviewer leaves time at the end and, where

necessary, in between the interview, for discussion. If appropriate or requested, a contact number of the ASBAH psychosexual counselling service is given.

Poor self image, health problems and sexuality are inevitably only some of the problems encountered by young people with spina bifida and/or hydrocephalus. whilst the results of our study to date remain incomplete, they already indicate some of the mechanical, emotional, and sexual difficulties experienced.

If you would like further information, or to participate in either of these studies, and you are aged between sixteen and twenty-five years and living within the north west Thames region or Kent, please contact Maddie Blackburn, Research Health visitor at the Community Paediatric Research Unit, Department of Child Health, Westminster Children's Hospital, London SW1- 2NS, tel: 081 746 8631. *Confidentiality will be assured and no individual will be personally identified in any of our reports.*

The community paediatric research unit would like to thank ASBAH for their financial support and the families for their contribution.

L LOOK INTO THE
FUTURE TODAY

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**The magazine for
young ASBAH
members**

**Winter issue
out NOW**

Features:

- ◆ Horse riding
- ◆ How to assert yourself
- ◆ Reaching new heights on a Mobility Week

*Contact Trish at
National Office*

to get your FREE copy

Be famous for a month

ASBAH has been chosen as one of a select number of disability organisations to provide pictures for possible inclusion in a lavish, full colour calendar for 1992.

The calendar is being produced by Sunrise Medical Ltd and they promise to pack it with information for disabled people of all ages - from details of exhibitions, to sport events. There will also be a guide to useful addresses and contacts.



ASBAH members are invited to submit entries to the competition to illustrate the months of January and February.

Whether it's a painting, drawing, embroidery, sculpture, print or photograph, your entry can be on whatever subject you choose as long as it has something to do with these months.

Entries will be judged by a panel of well known artists. The overall winner from all the charities involved will receive £250, second prize is £50 and third prize is £25. Every entrant will receive a calendar and their entry to the competition will be exhibited to the public at a special show at Naidex, at Alexandra Palace, in October.

Send your entry, with the form below, to LINK at National Office, marking the envelope 'Calendar Competition'. Closing date Friday 31 May.



The photographs used on this page were taken by a member of the Disabled Photographers' Society (Amanda Knapp who has a spinal injury). The Society welcomes members with spina bifida/hydrocephalus and could help you to develop your photography skills, contact them at PO Box 41, Wallington, Surrey SM6 9SG.

Application form for ASBAH entries to Calendar Design Competition

Name _____

Address _____

Postcode _____

Telephone no. (day) _____ (eve) _____ Date of birth _____

Type of entry: Painting Photography Drawing
(please tick appropriate box) Collage Needlework Other

Title of entry _____

"I hereby agree that the entry is all my own work, has not appeared in print before and, if selected, can be publicised wherever SUNRISE MEDICAL wish."

NB Please remember to name and address your work in order for originals to be returned.

Signed _____

Debate continues on Peto

“ As parents of a child who attends the spina bifida group at the Peto Institute regularly we have followed reports on ASBAH's assessment of conductive education by Carol Sobkowiak with great interest. We have discussed all we have read and heard about ASBAH's position on CE and have some recommendations to make in an effort to improve the present provision for children with spina bifida on their return to Britain.

We are not expecting 'miracles' for our child because we realise the full extent of her paralysis and know medically there is no cure, but we know that with precise teaching our child can learn to be independent. The children follow a full kindergarten education programme at the Institute which incorporates pre-reading and numeracy skills, independence training, mobility development and continence. Some children return home after receiving CE over a long period able to walk better or with less aids. Others learn to be dry and clean for 2 or 3 hours at a time and all are much less dependent on adults.

The most important aspect, however, is that the children know no limits. Our child does not know she should, by all accounts, be wheelchair-bound. She learns in a friendly atmosphere as an active participant in her lessons. She isn't forced to sit, as she did in her English integrated nursery, around the edge of the room whilst the able-bodied play and laugh. She is encouraged to climb, do forward rolls, play active games and develop a daring attitude to life. She was so passive, so quiet, before attending the Institute, now she will try anything from riding to skiing to swimming under water. We have a different child, motivated by excellent teachers and the love of her friends.

As a result of her positive attitude she entered normal school without a tear and her physiotherapist is rightly impressed by her ability to function so well. She can remove her coat and hang it up, she can tie her shoe laces, she can stand up again if she falls. The minutiae of life that can wear out a parent are taught at Peto in such a fun-filled way that children learn these skills because they want to. Many children can't wait to get to the Institute in the mornings to find out what they're going to be doing that day. There's an excitement about the spina bifida class that works to great effect.

In Britain our child receives physiotherapy once a fortnight alone, and has no occupational therapy. As regards continence management, our child was not encouraged to take an active part in her own care. Potty training should be taught at the usual age and if the Hungarian method is inappropriate, due to a reflux bladder, then catheterisation should be introduced at the same age. It is clear that early intervention is the key and pre-school children and their parents need more training.

There are flaws in our education system, as in many others. A recent HMI report on the education of physically handicapped pupils states that present provision in special schools, units and integrated resourced schools is at best adequate and at worst mediocre. There is no totally perfect education system but we have found that conductive education is the most complete, and despite all the emotional upheaval of splitting up the family and living apart whilst our child attends the Peto Institute, we believe our visits have been worthwhile.

We would like ASBAH to consider extending independence training courses at the Five Oaks Centre to under-fives and parents

to provide guidance and training for families. We want our child to attend normal school but we realise that children with physical handicaps gain much from working together in an atmosphere that encourages them to do things for themselves rather than being over-protected. Local Health Authorities could extend this idea to organising regular thrice weekly physiotherapy sessions for groups of under-five children with spina bifida. Good habits should be learned early in a playful atmosphere with professional guidance.

Many children receive no physiotherapy after the age of five and are somehow presumed 'cured' by the Health Authorities; whereas adults with sporting injuries receive regular physiotherapy. Anomalies such as these need investigation and correction. The physical welfare of disabled children cannot be left to voluntary groups such as Riding for the Disabled or local swimming sessions. Disabled children need to be just as active as able bodied children but their chances of being so are haphazard.

We would also like ASBAH to thoroughly research the work on spina bifida and related paraplegia at the Peto Institute and continue the dialogue which began with Carol Sobkowiak's initial assessment and develop it to include 'western medical opinion' and parents of children with spina bifida. A seminar would be an ideal starting point to develop closer links with Peto.

No one has all the answers regarding the treatment, care and education of children with spina bifida, but East and West have so much to offer each other and we would endorse any attempt to develop this first tenuous link with the Peto Institute and with the Birmingham Institute in the future. ”

Mr and Mrs Tippett

PS *We would be interested to know what ASBAH's position on Conductive Education is regarding children with hydrocephalus who attend the Peto Institute and are in various cerebral palsy groups."*

Editor's reply

After consultation with the relevant departments and Carole Sobkowiak, who produced a report on Peto for ASBAH, the editor replies:

Mrs Tippett's letter certainly contains many thought provoking points and ASBAH does agree that our educational system could learn from some of the practices followed by Peto. In particular, their task analysis approach could be used more in this country. We feel that more inservice training for teachers of young children is needed in task analysis, as well as motor stages of development and sensory motor programmes, and ASBAH is in touch with the Department of Education and the University of London to discuss ways in which this could be achieved.

On the matter of continence training we still have reservations as to the appropriateness of Peto's methods for our clients. Whilst we appreciate the value of undertaking potty training at the usual age, making both parents and children aware that training can and should take place, and the importance placed on independence and motivation - which is central to Peto's methods - there are also contra-indications. The group training method adopted by the Institute might leave the child unable or unwilling to function on his/her own and, unfortunately, Carole Sobkowiak, was not able to report favourably on the spina bifida groups she saw during her visit to Peto.

The health aspects of their continence training, for children with spina bifida, also concern us. ASBAH's continence advisers feel that renal function should be fully assessed and monitored

regularly. Staying dry is important but ensuring that the bladder is empty is, arguably, more important. Urinary tract infection through incomplete bladder emptying is a major problem and does not present as 'incontinence'. The same danger exists in bowel training. Staying clean is socially important but emptying the bowel is necessary for health and well being.

Mr and Mrs Tippett ask about younger children attending Five Oaks for independence training and, indeed, on a short course basis Five Oaks has had a few very young children, with their mothers, who came for help in developing skills appropriate to their age. They have attended individually or in groups of two, and parents have been able to stand back and observe - an essential requirement for child development and growth - and the children have been able to experience daily living tasks such as dressing, bathing, dealing with their own incontinence management, and mobility.

On the question of plans for future dialogue on conductive education, the Tippetts will no doubt be interested to hear that we are already liaising with the Foundation for Conductive Education in Birmingham on holding a seminar to discuss the whole issue of conductive education and spina bifida/hydrocephalus. Of course, medical staff from the Peto Institute in Hungary could join international meetings at the Research Society where there is already a forum for discussion and where they may find this country has a valuable contribution to make on the medical dimension of conductive education.

Finally, our reader suggests "thorough research" but, as Carole Sobkowiak has pointed out in the past we still do not have good or accurate data about the results of the Peto Institute for either the children in this country or abroad. We would like the staff at Peto to produce more concrete information about their results.

Join in



an ASBAH Study Day

▲ A consultant paediatrician explains spina bifida

▲ Our Disabled Living Team advise on

- *Managing Incontinence*

- *Mastering Mobility*

▲ A chance to take part in one of the three discussion groups

PLUS

A free information pack to take away

Bookstall - ASBAH's publications

Date 11 May 1991

**Venue: St Austell,
Cornwall**

*Further details from
Trish at National
Office*

Going to Sweden

As promised in our last issue we offer you some ideas of means and costs for travelling to Sweden this summer to take part in the IFHSB congress. The conference is being held on the Swedish Archipelago, outside Stockholm and flights to Stockholm are available from London Heathrow, Gatwick, or Stansted as well as Manchester and Birmingham.

The scheduled air routes from London Heathrow and Manchester are operated by SAS Scandinavian Airlines and British Airways. Flights from Gatwick are with BA and Air Europe and last year Birmingham European Airways started their scheduled service to Stockholm. Low cost charter flights, from £99, flying from Stansted, are available through Star Tour of Scandinavia, tel 071 706 2520 and Strata Travel, tel 081 805 1555.

Apex fares which can save you up to 60% on scheduled fares have to be booked at least 14 days in advance and you must stay a Saturday night in Sweden.

It is possible to travel London - Stockholm by coach via Amsterdam but the travel time is 47 hours, the cost is £166 return and you book through Euroline, telephone 071 730 8235.

If you prefer a sea crossing then



Cruising on one of the white Stockholm archipelago boats.

Scandinavian Seaways (telephone 0255 241243) sail from Harwich and Newcastle to Gothenburg. The trip takes around 24 hours with one way fares from £68 per person. You can take your car on the ferry, from another £42 per vehicle, or complete the trip on the Swedish State Railways using their trunk route between Gothenburg and Stockholm. The UK agent for Swedish Railways is NSR Travel, telephone 071 930 6666.

Just to remind you the congress itself runs from 14-18 August, the family week and young people's programme (for 13-25 year olds) begin earlier - on 11 August - and continue for the whole week. For further details on the congress and the week's holiday activities telephone Teresa Cole at National Office.

Table of Scheduled Air Routes to Stockholm

	Travel time	Frequency	APEX return	PEX return	Euro-Budget return
London-Stockholm	2hr 25min	8 daily	£233	£311	£386
Manchester-Stockholm	3hr 30min	1 daily	£242	£319	£478
SAS Scandinavian Airlines, tel 071 734 4020 British Airways, tel 081 897 4000					
London-Stockholm	2hr 50min	1 daily	£195	£261	£356
Air Europe, tel 0345 444737.					
Birmingham-Stockholm	2hr 20min	5 weekly	£236	£308	£510
Birmingham European Airways, tel 021 782 0711					

Diary Dates

25-27 February - Behavioural Difficulties in Children with Special Needs - a workshop on behaviour modification and observation techniques at Castle College, Wallingford, Oxon. £169 including accommodation. Tel: 0491 37551.

18 March - Introduction to Wheelchair Sport - 'sportstart' beginners' course run by Wheelchair Sports Foundation, basic skills and techniques, including concepts of fitness. Contact the Sports Administrator at Guttman Sports Centre, Harvey Road, Aylesbury, Bucks HP21 8PP, tel: 0296 84848.

25 March - Junior Week - Basketball. 'Sportstart' beginner/intermediate level course, Guttman Sports Centre.

1 April - Wheelchair Basketball Coaching Camp - 'sportstart' intermediate level course, contact, as before.

13 April - ASBAH's Hydrocephalus Support Group Study Day, at Eastern Region Office 56 Camberwell Road, London SE5 0EN. Open to parents (£4) and professionals (£15), including a talk by consultant paediatric surgeon, Mr Zeid Tabbara and group sessions with our disabled living advisers. Contact Trish Jones at National Office on 0733 555988 for further information.

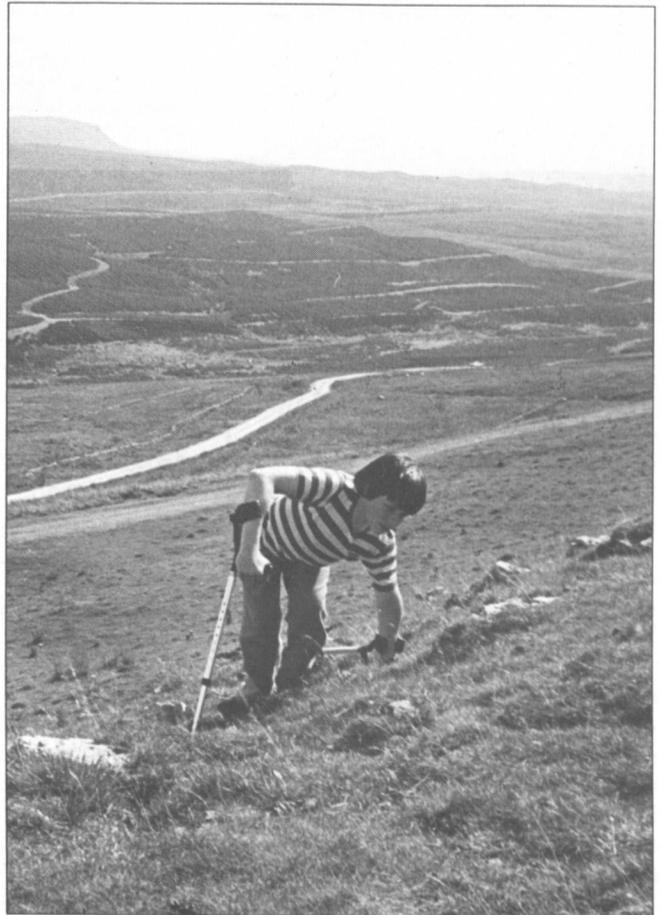
15 April - National Star Centre for Disabled Youth - three day residential sports course for 14-17 year olds. £10, including full board and coaching. Tel: Cheltenham (0242) 527631 for more details.

Five Oaks Holidays

FIVE OAKS in Yorkshire is not just a residential training centre - they also run holiday weeks throughout the school holiday periods. These provide an opportunity to have a break where you can enjoy peace and quiet in the beautiful gardens and surrounding countryside or take part in trips out and more energetic activities.

Of course there are also opportunities to be adventurous on one of Five Oaks Outdoor and Recreational Pursuits Courses where you could try activities as diverse as abseiling and arts and crafts and most things in between! For those with a wanderlust spirit there are 'day tripper' weeks where every day provides a different destination from the east coast to excursions into Bronte country.

The Five Oaks programme for 1991 starts this month and carries on right through to next year. Below we give dates for holidays and courses from April to October.



A young holiday maker exploring the countryside near Five Oaks in Yorkshire

1991/2 Activity Courses and Holidays Weeks at a Glance

April:

30 (March) to 6 - Holiday Week
14 to 20 - Fashion Course
21 to 27 - Driving Course

May:

1 to 6 - Wildlife Conservation Course
25 to 1 (June) - Holiday Week

June:

2 to 8 - Day Tripper Week
15 to 22 - Wildlife Week
28 to 30 - Fishing Weekend

July/August:

13 to 20 - Outdoor and Recreational Pursuits
20 July to 31 August - Holiday Weeks

September:

31 (August) to 7 September - Outdoor and Recreational Pursuits
22 to 28 - Driving Course

October:

11 to 19 - International Fashion Course
19 to 26 - Holiday Week

November:

12 to 14 - Driving Assessments
28 to 3 (Dec) - Wildfowl Watching

December:

4 to 8 - D. J. Course
21 to 2 (Jan) - Holiday Weeks

How to book

Bookings can be made at any time as the Centre is open throughout the year. Provisional bookings can be made over the 'phone, but please note, we can only confirm acceptance of your place on receipt of your completed application form.

For all enquiries, forms and bookings please contact Sarah Peet, Five Oaks Centre, Ben Rhydding Drive, Ilkley, W. Yorks LS29 8BD. Telephone 0943 603013

Shopmobility

The historic university city of Cambridge has joined those towns offering a shopmobility scheme. The service offers electrically powered and manual wheelchairs for shopping and use of other facilities in the city centre. Cambridge shopmobility is open from 10.00am to 4.00pm on Wednesdays and Thursdays.

There is no hire charge for using the wheelchairs. For further details telephone 0223 463370.



New name for sports organisation

The British Paraplegic Sports Society has changed its name to The British Wheelchair Sports Foundation to more accurately

reflect its activities. The foundation holds courses in a range of sports throughout the year. Different courses cater for beginners and those at intermediate level as an introduction to wheelchair sport, or to provide further coaching. All the activities are held at the Guttman Sports Centre, Aylesbury - see *Diary Dates* for details of forthcoming courses.

The Disability Benefits Bill

- making your voice heard

THE new disability benefits Bill is currently being debated in Parliament and is expected to receive Royal Assent in early April. The Disability Alliance feels the Bill is being rushed through parliament without the necessary time for concerned organisations to thoroughly discuss its implications and pursue changes they feel are necessary.

The Bill (The Disability Living Allowance and Disability Working Allowance Bill 1990):

- ❖ introduces an amalgamated version of attendance and mobility allowance with some variations. In particular, a new lower mobility and a lower care rate will be payable at a proposed £10 per week. This allowance is to be re-named the "Disability Living Allowance".

- ❖ proposes a new means-tested "Disability Working Allowance" for people who have been on incapacity or certain other benefits who take up very low paid work.

- ❖ revises slightly the assessment and decision making system for both allowances. The Bill removes the Attendance

Allowance Board, reduces the medical input into the initial assessment and adjudication of claims, allows mutual decisions to be taken by lay adjudication officers and introduces a new tribunal body - the Disability Appeal Tribunal.

Clause 5 of the Bill gives the Secretary of State very general powers to write future regulations to determine what will happen to current mobility and attendance allowance claimants. Whilst one should expect that all current recipients would continue to get their current rate of mobility or attendance allowance, for the remainder of their current period of award, Disability Alliance seeks assurances that this will be the case.

In particular, assurances must be given that the changeover is not used as an opportunity to initiate reviews of people's awards ie to push them on to the new lower rates.

What YOU can do

The Disability Alliance is asking individuals and groups to make their views felt on disability benefits and to write or speak to their own MPs NOW to draw their attention to the legislation being discussed in parliament.

The Alliance suggests that you tell your MP

- what it's like to be a disabled person living on benefits - explain the extra costs you have because of your disability.

- that a disability income, which will give disabled people a decent standard of living, is needed which will provide for the extra costs you incur for example more money for heating, diet, laundry etc.

- point out that the Disability Living Allowance outlined in the current Bill goes nowhere near enough, it's the merger of two existing benefits and helps very few people.

If you have any comments to make on the legislation or require further information on the contents of the bill, write to LINK or contact *Disability Alliance*, 25 Denmark Street, London WC2H 8NJ.

This article has been compiled from information supplied by the Disability Alliance - a federation of over 80 organisations of and for disabled people of which ASBAH is a member.

Severe Disability Premium

A TEST CASE has left the way open for up to 400,000 people to claim eligibility for the severe disability premium.

Entitlement to severe disability premium has been restricted to those who qualify for income support, housing benefit or poll tax rebate and who receive attendance allowance but also *do not* have a carer who receives invalid care allowance or non-dependent adults living with them. As a result of the test case a

social security commissioner has ruled that the last two conditions are beyond the power of the Social Security Secretary to impose.

At the time of going to press the government is appealing against the ruling but meanwhile don't delay in applying if this means you could qualify. You may also be able to get the premium backdated. Before you claim contact your fieldworker for details re the current position.

December Link

Following the article in the last issue of Link on SDA and Training Allowances, we have been asked to make it clear that while SDA entitlement is not affected, it is NOT possible to get both SDA and a Training allowance at the same time.

Benefits to go up

Disability benefits are to rise in April as part of a £900 million increase in Government spending in this area. This table shows the benefit rate alterations.

	Old rate	New rate
	£	£
MAIN BENEFIT RATES		
Attendance Allowance		
- lower	25.05	27.80
- higher	37.55	41.65
Invalid Care Allowance	28.20	31.25
Invalidity Benefit		
Invalidity Pension	46.90	52.00
Invalidity Allowance		
- lower	3.10	3.45
- middle	6.20	6.90
- higher	10.00	11.10
Mobility Allowance	26.25	29.10
Severe Disablement Allowance	28.20	31.25

INCOME SUPPORT

Maximum amounts for accommodation and meals in residential care homes

Physical Disablement		
- under pension age	215.00	230.00
- over pension age	155.00	160.00
Mental Handicap	180.00	195.00
Maximum increase for Greater London	23.00	33.00
Nursing Homes		
Mental Handicap	225.00	260.00
Physical Disablement		
- under pension age	255.00	290.00
- over pension age	210.00	255.00
Maximum increase for Greater London	23.00	33.00

INCOME-RELATED BENEFITS

Income support, housing benefit and community charge premiums added on to main benefits

Disability		
- single	15.40	16.65
- couple	22.10	23.90
Severe Disability		
- single	28.20	31.25
- couple (one qualifies)	28.20	31.25
- couple (both qualify)	56.40	62.50
Disabled Child	15.40	16.65
Carer	10.00	10.80

EARNINGS RULE

Invalid Care Allowance	20.00	30.00
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PRODUCT NEWS

Cushion the pressure!

A cushion designed to prevent the pain of pressure sores for wheelchair users has been developed by Karomed.

The Transflo 600 cushion is waterproof and vapour permeable. It contains a fluid membrane which spreads and evens out pressure over the body support points.

The cushion is available in three sizes including a paediatric one.

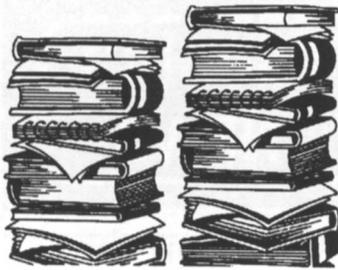
Wheelpower

A BRIGHTLY COLOURED, lightweight, folding, powered, chair is the latest offering from Sun Rise Medical. The chair has been designed with the needs of active, fashion conscious users in mind



and is now available in red or blue with more colours available this spring, including neon.

The firm claims to have used the latest advances in hang glider technology to give the framework durability with the maximum lightness.



BOOK SHELF

varying levels of ability and motivation can be taught together. Although written primarily for teachers they are also useful reading for parents and all those concerned with integrated education.

Holidays in the British Isles 1991 - A Guide for Disabled People

This is the 16th edition of RADAR's publication which sets out to provide the answers disabled holidaymakers need to those questions which could make the difference between an enjoyable holiday and one marred by unforeseen problems - Will a wheelchair fit in the room? Are there handrails in the bathroom? Is there any accessible transport?

Holiday accommodation covered in the book includes hotels, holiday centres, self catering cottages and caravan sites.

Priced at £4.50 inc p&p the guide is available from RADAR at 25 Mortimer Street, London W1N 8AB or from branches of WH Smith and Sherratt and Hughes

Disability Arts Magazine

A new quarterly magazine which aims to cover everything connected with the arts and disabled people is due out in late March.

The spring issue will include an interview with the new Arts Minister, fiction, photographs, cartoons, poetry, reviews and news.

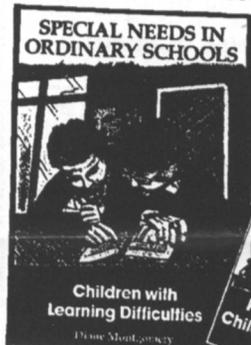
Funded by the Arts Council and Regional Arts Associations it is available on subscription from 10 Woad Lane, Great Coates, Grimsby DN37 9NH at a cost of £12 for four issues.

Our Homes, Our Rights

This report from Shelter, by Dr Jenny Morris, looks at 21 local

authorities to see how far they are meeting the housing needs of disabled people. It shows that some local authorities have little knowledge of either the supply or demand of suitably designed or adapted housing for disabled people and few authorities have comprehensive policies which would enable independent living. On the other hand, the report highlights examples of good practice and gives

recommendations for



developing and implementing better housing and support

services for disabled people. Copies of the report are available from Shelter, 88 Old Street, London EC1V 9HU, price £2.50 (individuals) £3.50 (institutions).

Special Needs in Ordinary Schools

Cassell Educational have published three more books in this series aimed at teachers trying to meet special educational needs in the context of the ordinary school classroom. The books all offer practical guidance on ways in which children with

Pre-School Provision for Children with Special Needs

Written by Brenda Robson, who is a practising educational psychologist, this volume looks at the changes needed to enable ordinary nursery schools and classes to integrate children with special needs.

Practical aspects covered include staffing, the role of parents, record keeping, assessment and professional support services.

Children with Learning Difficulties

In this book, Diane Montgomery seeks to identify learning difficulties, looks at teaching methods and strategies for dealing with them, and discusses the research into the effectiveness of these methods. A chapter is also included on managing the behaviour of children with learning difficulties.

Children with Physical Disabilities

After outlining the most common physical disabilities in children, including spina bifida and hydrocephalus, this book looks at ways of providing access to the curriculum for these children. Practical aspects of disability in the school environment are covered such as mobility and continence management.

Communication, language and learning are discussed as well education for living - leisure and recreation, sexuality and independence.

The author, Paula Halliday, was a headteacher of a school for pupils with physical disabilities and is now an advisor for special educational needs.

ADVERTISING

FOR THE USE OF LOCAL ASSOCIATIONS
AND OTHER READERS

Rates: £3 for 30 words max; £4.24 for 30-45 words;
£5.50 for 45-60 words.

Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of Link (April) should be submitted by Friday, 8 March. Please send them to: The Editor, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

HOLIDAY ACCOMMODATION

When booking, check to make sure the accommodation suits your particular needs.

SELSEY, SUSSEX

Fully-equipped, six-berth mobile home. Ramp access, and designed for wheelchairs. Site near sea. Heated pool. Clubhouse. Details Mrs C Bugden, 27 The Grove, Sholing, Southampton SO2 9LT, tel 0703-444921.

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Views of sea, Exmoor, steam railway, close to beach. Privately situated terrace of four, fully accessible, bungalows equipped to high standard. Colour television, video, laundry, games room. Linen, electricity included. For full details, tel Lorraine or Martyn Babb, Dunster (0643) 821200.

BORTH NR ABERYSTWYTH

Six berth caravan. Suitable for large wheelchairs. Licensed site. Five minute walk to sea, shops etc. Details: Mrs J Carter, 1 Meadow Road, Craven Arms, Shropshire SY7 9QY

WESTWARD HO!

North Devon holiday chalet, sleeps six. Near sea, club, swimming pool. Shop on site. SAE to Mr Oakley 12 Farleigh Road, Perton, Wolverhampton. Tel: 751484.

WINTERTON-ON-SEA, GREAT YARMOUTH, NORFOLK

Six berth chalet overlooking sea. Exclusive holiday centre providing the ideal setting for a relaxing holiday in peaceful surroundings. Heated pool, club, shop etc. Further details Fred Simmonds (0628) 783413, 18 Ashcroft Road, Maidenhead, Berks SL6 6JF.

LOOE, CORNWALL

Fully equipped, self-catering two bedroom bungalow. Sleeps six. Site near sea with easy access to beach, shop and camp facilities. Easily accessible for wheelchairs. Details: Mr P Cash. Tel. 0425 72055.

FOR SALE

BEC SUPA SCOOTER. Scarcely used. Complete with standard batteries, automatic charger, battery gauge, horn, walking stick clip, folding seat and arm rests, shopping basket and weatherproof cape. £500. Tel: 021 73268 (Bromsgrove).

BUXTON, DERBYSHIRE.

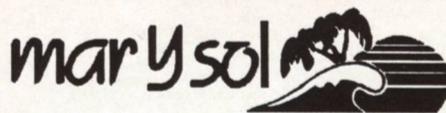
Ground floor self-contained flat in Victorian building. Suitable for wheelchairs. Parking right outside the front door. Two large bedrooms, sitting room, kitchen/dining room, bathroom, separate toilet. £65,000. Tel: Mrs Ruth Parker on 0625 613068 for more details.

S/HAND LIGHTWEIGHT WHEELCHAIRS for sale. Tel: 081 742 1620

BEC 'SUPASCOOTA' 4/5 years old, immaculate condition. Battery charger included. £2,000 new - now £550. Also **WHEELCHAIR** vgc with cosy body/leg warmer. £150 ono. Tel: Mrs Myles on 0223 833963 (Cambridge).

ORTHOPAEDIC CHILDREN'S SHOES. Beautifully designed by a German company and made in Italy. For more information telephone Mrs A M Asgari on 071 263 3373.

FIAT FIORINA CAR. Converted with hydraulic lift. Metallic grey, 8000 miles, immaculate condition, 18 months old. £7,500 ono. Tel: 0254 53429.



SUNNY TENERIFE OR SCENIC WALES

For 10 years families have taken holidays at our self-catering bungalow (sleeps 4/5) in Mold.

Now, as the UK Representative for the beautiful, fully accessible Mar Y Sol resort in Los Cristianos, Tenerife, I can arrange a holiday you won't forget!

"Brilliant, amazing" says BBC TV's The Travel Show. You won't be disappointed.

Brochures - Mold or Mar Y Sol, contact Lynne James, 7 Overpool Road, Ellesmere Port, South Wirral L66 1JW. (Tel: 051-339-5316).

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