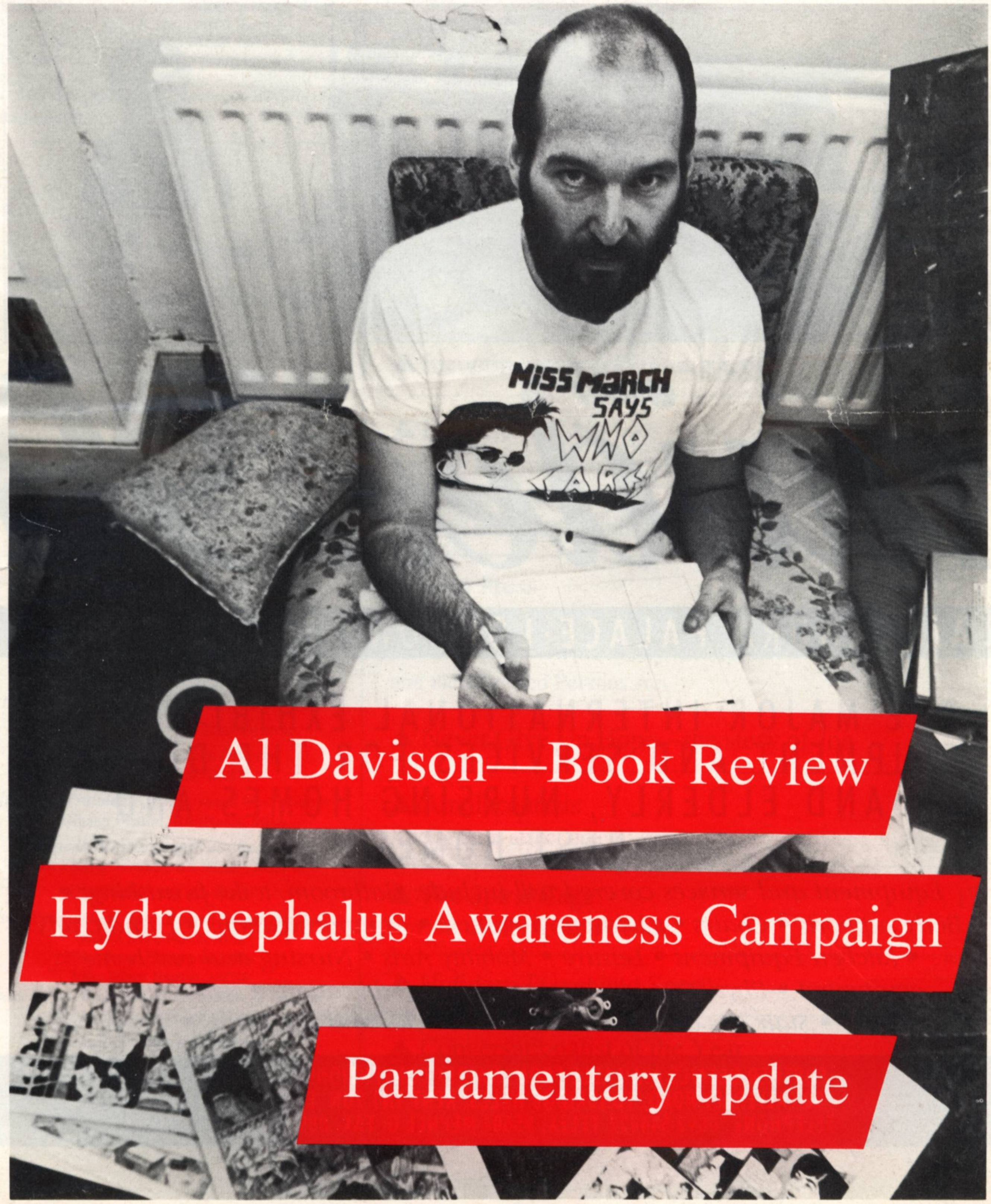
June 1990 No. 128 30p

The magazine for people with spina bifida and/or hydrocephalus

Link



Al Davison—Book Review

Hydrocephalus Awareness Campaign

Parliamentary update

DISCOVER INDEPENDENCE AT

naidex '90

ALEXANDRA PALACE · LONDON · 17-19 OCTOBER

THE MAJOR INTERNATIONAL EXHIBITION OF EQUIPMENT AND SERVICES FOR THE DISABLED AND ELDERLY, NURSING HOMES AND REST HOMES

Equipment and services covered will include: Bathroom/toilet furnishings • Body supports • Chairs • Childrens furniture • Communications • Handicrafts • Kitchen Equipment • Leisure • Mobility Aids • Nursing and rest home equipment • Physiotherapy/exercise aids • Publications • Rehabilitation equipment • Stair lifts and hoists • Toys • Vehicles and adaptions • Wheelchairs

FURTHER DETAILS AVAILABLE FROM: NAIDEX CONVENTIONS LIMITED
90 CALVERLEY ROAD, TUNBRIDGE WELLS, KENT TN1 2UN, ENGLAND
TELEPHONE: 0892 544027. TELEX: 95604 MEPNCL G. FAX: 0892 541023

Link

JUNE 1990 ISSUE NUMBER 128

Cover Picture: Al Davison, author of *The Spiral Cage*
Photograph by Stewart Bonney

contents

The magazine for people with spina bifida and hydrocephalus

Editor: Monica Hart

Published by ASBAH,
ASBAH House
42 Park Road
Peterborough PE1 2UD
Telephone 0733 555988

LINK SUBSCRIPTION 6 EDITIONS - 12 MONTHS

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

All payments should be made in Sterling.

Copyright 1990. Reproduction of any material, in part or in whole, contained in *Link* is strictly forbidden, either at home or abroad, without the prior consent of the publishers. Opinions and views expressed in this magazine are not necessarily those of The Association for Spina Bifida and Hydrocephalus. Whilst every care is taken to ensure accuracy of information published in *Link*, the publisher can accept no liability.

Registered charity no. 249338

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Patron: HRH The Duchess of Gloucester, GVCO
President: Mr Jeffrey Tate
Chairman: Mr Patrick Daunt
Hon Treasurer: Mr A K Stewart-Roberts

SENIOR STAFF
Executive Director:
Miss Moyna Gilbertson, MCSP, FBIM
Finance Director:
Mr Derek Knightbridge, FCCA
Appeals Director: Mrs Jennie Whiting
Assistant Director (Administration)
Mr Paul Dobson, BA (Hons), MIPM
Fieldwork Manager: Mrs Teresa Cole, MICA
Publicity Manager: Mr Tony Britton
Research & Information Officer:
Miss Pat Corns, SRN
Education, Training & Employment Coordinator:
Mrs Susan Fenton, BA (Hons), MBA
Regional Development Coordinator:
Mr Phillip Watson, BA (Hons), RGN
Disabled Living Advisors:
Service Manager: Miss Rachel Stanworth, BA (Hons), SRN, PGCE, MSc
Miss Anne Burgoyne, SRN
Miss Mary Barton, MCSP
Mrs Leonie Holgate, MCSP, Mr Jamie Gilham
Mr Ian Laker, Mr John Naude
Five Oaks Centre Manager:
Miss Joan Pheasant, NNC
Marketing Manager: Mr Roy Johnston
Trusts/Legacies Administrator:
Mr Peter Cox

GOING DUTCH WITH THE WOLVERHAMPTON WANDERERS

In September last year, our group members—the Wolverhampton, Sandwell and Dudley ASBAH, went to Valkenburg in Holland for a weekend break. It was a brilliant weekend: everyone had fun and thoroughly enjoyed themselves.

The weekend was the most ambitious thing our group had ever attempted as normally we have day outings. The whole excursion was planned and mapped out like a military manoeuvre! Steve Breslin from Haylin Travel was our Travel Agent and advisor and working closely with our group, the holiday was devised. Steve attended meetings, to explain to us all about the holiday in general, the hotel and travel arrangements; suitability for our wheelchairs, etc., was priority, and we had a special coach booked for our trip, fitted with a lift.

It was a brilliant weekend: everyone had fun and thoroughly enjoyed themselves.

The weekend break was financed by a combination of fund-raising—i.e., one of our members, Jane Oakley, did a sponsored swim, someone else attempted a sponsored slim and we did our usual Flag Days, etc. We also received money from the ITV Telethon Appeal—all of which made our weekend possible. Our party consisted of 15 SB members whose ages ranged from 8 years to 29; we took 14 wheelchairs and everyone took along a carer. A few Dads came along too, to add a bit of muscle!

On Friday evening our members gathered at the various 'pick-up' points—it was so exciting waiting for the coach and the start of our Dutch adventure. A few of us were a little nervous and apprehensive about the ferry trip across the Channel from Dover to Ostend, and perhaps, also, about the thought of being so far away from home—but even those few butterflies jumping about didn't manage to dampen the excitement and thrill that we all felt—the anticipation of the weekend ahead.

Before long our coach was full and we started our journey down the M6/M1/M25/M2 to Dover—stopping en-route, of course, at the Services for the loos, and managing without any trouble at all. One concern had been the Disabled Toilet facilities on the foreign motorways; we were yet to find out what they were like!!

On arrival at Dover we boarded the PO ferry, The Prince Albert, which would take us to Ostend. The ferry was manned by a Belgian crew, who made us feel very welcome and all of us enjoyed our overnight crossing. The majority of us were able to tuck into a fried breakfast at around 6.30 am on the Saturday morning, before finally docking in Ostend at 9.00 am. However, that was when the fun started! We were taken down to the vehicle deck via one of the lifts, only to find that when our driver Elizabeth, came to operate the lift on our coach it wouldn't work! Apparently, the electronics had decided to 'go on strike', and despite trying as they might, neither Elizabeth nor anyone else could get them to work and so that left all us stranded, at the side of the road.

By this stage, all the other vehicles had been driven off and it was just our coach that was defiantly standing there, all alone, and holding up The Prince Albert on its cross-Channel schedule! The ferry crew tried to tow the coach off, but the hydraulic brakes were on and they couldn't move it an inch—the only thing to do was to try and contact the local Volvo garage to see if they would send out a mechanic to Ostend to fix it. So, whilst we waited, the Ostend Dock people took our group to the nearby railway station where the loos, etc., were all opened up for us and a waiting room provided for our use.

Nothing was too much trouble for anyone. One Belgian sailor on our ferry even offered to take me home with him—you can't ask for better treatment than that! Of course, we thought the whole episode was hilarious and we had plenty of laughs during the few hours we were in Ostend.

Finally, the mechanic did manage to get the electronic system working again and the coach was driven off the ferry; we were all loaded on board and set off. Before we could head off for Valkenburg, the mechanic insisted that we go to the garage with him for a final check to be made to the system—so we had a pleasant drive into Belgium before eventually setting off for Valkenberg.

The coach ride through Belgium and into Holland was smashing—it was fascinating seeing the foreign motorways, etc., and driving on the different side of the road. We also soon found out that the standards of the disabled loos at the Services abroad were fine—excellent, in fact. No problems were encountered at all, so that was a relief (in more ways than one!).

One Belgian sailor on our ferry even offered to take me home with him—you can't ask for better treatment than that!

We stayed at the Hotel Lennards—right in the heart of Valkenburg, an extremely pretty town with the Castle ruins high up on the hill. At first we all thought our rooms were rather small—but everyone soon settled in, and by the end of our weekend we had all become very attached to them, all of them had their own bathroom, of course. The food was 'different', especially the breakfasts with cheese and ham in abundance, and fruit loaf; but it was all smashing!

Saturday evening was spent walking around the many shops that stay open late for the visitors, and sitting outside the numerous pubs and cafes, etc. One of the many charms of the Continent is being able to sit outside, either eating a meal or having a drink, and watching the world go by— Lovely!

On the Sunday, Steve, who had travelled with us as courier, had organised a day out at Eindhoven. As I had to have medication that day I couldn't go with the rest of the gang—but it was a lovely warm, sunny day, so once I was feeling better we spent the day leisurely walking around the town and sitting taking in the atmosphere of Valkenburg, and the people there. After dinner, we all set off for a final fling round the shops, getting our last few pressies and souvenirs and, of course, having the obligatory drink before retiring for the night before our early start the next morning.

Surprise, surprise. No-one wanted to leave after breakfast on the Monday morning—it had been such a fantastic weekend and we were all really sad about leaving. All the wheelchairs were loaded on, Elizabeth started the engine, and the coach began to move away from the hotel. The journey back up the motorway to Zeebrugge was wonderful—the sun was shining and I was, as usual, waving to the lorry drivers that we passed (they waved back of course!), and everyone on the coach was joking that we'd probably have a convoy of foreign lorries and drivers behind us when we got to Zeebrugge!

The ferry—The Pride of Dover—was brilliant, and the weather was still glorious as we sailed across the Channel—many of us sat outside on deck and, to be honest, it could easily have been a cruise ship, everything was so perfect! Our ASBAH members sort of took over the ferry on the return trip; facilities were excellent and the crew and other passengers really seemed to enjoy having us on board, and to see us having such a good time. If there were any nerves at the beginning of the weekend, well, they had all long since gone, and everyone was just having fun!

All too soon, the White Cliffs of Dover came into view. Within a short time we had disembarked—no problems this time—and we started our drive up the motorways. Like most return journeys, we seemed to fly along, and all too quickly we were having to say our goodbyes after an unforgettable weekend. It was truly wonderful!

For my own part, the holiday was especially beneficial to me because I was going into hospital the next month for major surgery and I know that all the very happy memories of that weekend in Valkenburg have definitely helped me through my weeks of recovery. I know it helped many of our other group members too.

... to be honest, it could easily have been a cruise ship, everything was so perfect!

We are hoping very much to be able to have another holiday in Valkenburg next year—we shall try to have a complete week away, though, next time —so inevitably, we've got to start collecting the monies again! Flag Days, etc., are planned to start the ball rolling, as it were!

The weekend that we had was, to a great degree, funded by the donation from the Telethon Appeal, and on behalf of all the members of the Wolverhampton, Dudley and Sandwell ASBAH—a huge THANK YOU to everyone who contributed to that Appeal. Many thanks, also, to Eric and Steve for getting the whole show off and on the road, as it were! And thanks to everyone who helped us—it was brilliant!

From Jackie and all our Group Members.

SOCIAL SERVICE INSPECTORATE REPORT

The Disabled Persons (Services, Consultation and Representation) Act 1986 is one of the most important pieces of legislation for disabled people since the 1970 Chronically Sick and Disabled Persons Act. Three years after it received the Royal Assent the Social Services Inspectorate carried out a survey into the extent to which those parts of the Act which have been implemented (see *Link* No. 124) have been implemented in practice.

The Report issued in January 1990 shows a patchy implementation of the Act with a number of social services departments attributing lack of progress to a lack of funds from central Government. The Report concludes:

"The Act served the invaluable functions—some 17 years after the CSDP Act—of raising the profile of disabled people, of legislating afresh for their needs and those of their carers, and of providing a legislative framework for good practice. It was hoped that local authorities and social services departments would respond as effectively and speedily as they could.

From the evidence provided by this inspection, it appears that for some SSDS the Act has enabled them to develop services from a low base and in others, where existing practice was reported to be of a high standard, it has enabled and encouraged fine tuning. However, for many local authorities —for a variety of reasons—there is much to do, with intentions needing urgent translation into action."

This important report is available from the Department of Health, Social Services Inspectorate. Here follows its summary and recommendations:

'DEVELOPING SERVICES FOR DISABLED PEOPLE'

THE OPERATION OF THE DISABLED PERSONS (SERVICES, CONSULTATION & REPRESENTATION) ACT, 1986

SUMMARY AND RECOMMENDATIONS

Introduction

This report describes the findings of an inspection by the Social Services Inspectorate into the extent to which social services departments are operating those Sections of the Disabled Persons (Services, Consultation and Representation) Act 1986 that have been implemented to date.

The inspection was carried out between March and June 1989 in a one-in-three sample of social services departments in England. Information was collected on postal questionnaires, and from written policy and position statements. It was part of a programme of inspection activity focussed on the Act.

As the inspection was specifically geared to look at the implementation of the Act, other developments in some of the sampled local authorities to maintain and improve general services to disabled people are only referenced in the report where details were made available and are relevant.

Overall conclusions from the inspection

The broad conclusion from this inspection is that the Act has enabled some social services departments to develop services for disabled people from a low base and other social services departments to fine tune existing practice. However, for many local authorities there is much to do, with intentions needing urgent translation into action.

The patchy implementation of the Act across the country is exemplified by the wide range of spending within and between classes of local authority. Some authorities had yet to allocate any funds to the operation of the Act, while others had allocated large amounts.

A number of social services departments attributed the lack of progress in operating the Act to a lack of resources. Some criticised central Government for this (despite the fact that recent Rate Support Grant settlements have recognised the need for local authorities to spend in this area). Others pointed out that funds which might have been used in relation to the Act 'get lost' within the local authority. Accordingly, some social services departments argued for a specific grant. These reported resource shortfalls—however attributed—present potentially serious problems for the development of services for disabled people. They need to be considered further in the context of future discussions between central Government and the Local Authority Associations on personal social services financial issues.

However, it is possible to infer from both the inspection and on-going contacts with the field that often service developments for disabled people are given a lower priority than service developments for other groups of service users and other local authority service committees.

Other key findings from the inspection

While some local social service committees had agreed written policies on the Sections of the Act, most social services departments reported such policies either had not been agreed or were not needed (as existing practice was good enough). However, the evidence from the inspection suggests that social services committee policy can provide a framework for and facilitate operation and change. Written policies can also be shared with other agencies and service users, and so lead to better local understandings between all those concerned with the provision of service.

Despite the fact that some London social services departments reported that aspects of the Act were part of existing practice, the general lack of policy statements, the lack of certain operation changes and low levels of funding in London all add up to concern about the operation of the Act within the capital.

In a large number of local authorities much operational change in respect of Section 4 (the duty to assess the need for services), Sections 5 & 6 (the identification and assessment of disabled school leavers) and Section 8(1) (the duty to take account of carers' abilities) was still to be introduced or planned. It was not reassuring that timetables for the introduction of change were sometimes vague. In particular, there must be doubt about whether some social services department can make the necessary arrangements for 1990 school leavers within the requirements of the Act (a follow-up inspection will report in more detail on this matter).

While occupational therapists have a key role to play in assessing the needs of disabled service users, in some social services departments there appeared to be an over-reliance on staff in the assessment process. Assessments need to be comprehensive and as such will often need to be compiled by a number of staff including social workers and possibly personnel from other agencies, as well as occupational therapists.

In their responses social services departments demonstrated that they were appropriately concerned to consider the abilities of carers and to involve them in service planning. However, more could be done to involve carers as recipients and co-presenters of training. It was of concern that in London carers' needs are possibly being overlooked.

Section 9 of the Act covers the provision of information. It was discouraging that so little had been done by social services departments to provide relevant information in suitable formats for disabled people and carers. Social services departments seemed to recognise this as a poor situation, and many were planning to prepare information booklets for public use.

Local authorities appeared to give due consideration when formulating policies relating to the Act to the needs of minority groups, including minority ethnic groups. However, there is cause for concern in that little information about services was made available to people for whom English was not the first language, and much training did not address the needs of minority groups.

In relation to Section 10 of the Act, despite a great deal of resolve among the sampled local authorities to make co-options of people with specialist knowledge of disability to council committees, there was a gap between intent and practice. There was apparent confusion in the way that Section 10 should be interpreted. Section 10 actually requires local authorities to consult with organisations of disabled people when making such co-options. Some local authorities thought they were operating according to the Act by consulting with voluntary organisations concerned with disability. London social services departments seemed not to have a positive stance towards Section 10.

The majority of social services departments reported that training in relation to the Act had taken place, much being carried out jointly with other statutory agencies and voluntary organisations. However, much of the training appeared to be piecemeal, whereas the need is for training that is based on a strategic consideration of the needs of staff and services users alike.

Recommendations

There are a number of key recommendations to emerge from this report. Most of them concern social services departments and their social services committees (grouped together under the term 'social services authorities'.) It is hoped that due consideration of these recommendations can, resources permitting, lead to action by those local authorities yet to make much progress in operating the Act.

Social services authorities should put in place arrangements for 1990 school leavers as required by Sections 5 & 6 of the Act.

They should also review, and where possible bring forward, timetables for introducing operational changes to meet the other requirements of the Act.

Social services authorities in London need to review the extent to which they take account of the needs and attributes of the informal carers of disabled people when planning and delivering services.

Social services departments should ensure the availability of relevant information about their own and other services to disabled people in suitable formats—such as large print, braille, languages other than English.

Social services authorities should progress the direct involvement of disabled people in the strategic and operational planning of services at both elected member and officer levels.

Finally, the reported shortfalls of resources for the operation of the Act need to be considered by central Government and the Local Authority Associations in their future discussions on personal social services expenditure.

(Note: these points are discussed in the relevant Chapters of the main body of the report, and are brought together more fully in Chapter 10— 'Discussion and Recommendations'.)

A SPECIAL CHILD IN THE FAMILY

"Although a child's disability might vary, the parents problems always seem to be the same " says Diana Kimpton, author of *A Special Child in the Family—Living with your Disabled Child.*

The contents of the book are drawn from personal experience, listening to other parents and a great deal of research.

40 year old Diana Kimpton from the Isle of Wight has written the book for which she searched in vain when her two sons aged 13 and 14 were diagnosed as having cystic fibrosis. The ideas in it are parent-sized ones. "I have tried to give help and advice on how to cope with the emotional and practical problems of caring for a child with special needs." The book tackles subjects often avoided such as failing to cope, putting a child into care and caring for a dying child.

"I guess what I am trying to say throughout the book is that it is all right to feel sad and guilty. When I found out that my children were disabled I just wanted someone to tell me that it was all right to feel so bad.

"I want people to know that you do not always have control of your emotions. One should not feel bad about feeling. There are days when I can cope, there are days when I can't. I have had to accept that it is not wrong to ask for help. Just the ability to talk to someone outside the immediate family can be a great comfort" Diana continues.

"One of the most difficult times is when a child is in hospital. You feel that you are neglecting the rest of the family if you spend all your time with it. On the other hand when you are at home, you feel bad about not being at the hospital. I have tried to offer practical information, like don't assume that all the hospital staff will be acquainted with your child's condition. You might have to teach them to lift or feed him or her. It is no good thinking that just because you have spoken to one nurse on the ward, all the others will understand.

"I am also keen to look at the option of keeping a child out of hospital as much as possible. Sometimes, the whole family is so emotionally exhausted and the child is so fed up with always being in hospital, that it might be worth asking the Consultant whether the operation can be deferred for six months.

Diana Kimpton

"I guess acquiring the skills to make a fuss and ask questions was my favourite part of the book to write. It is so easy to take off-handedness personally. It is important to remember that doctors are people first and medics second. They can also be over-tired,or have just lost a close friend.

"The way professionals communicate is also important to appreciate. For example it is natural for a Consultant to write to one's GP and keep him or her informed of treatment. It is unlikely for that communication to go the other way and Consultants rely on patients to keep them informed."

The ability to say 'no' is a skill Diana touches on in her book and is something everyone would like to be able to acquire. "Don't do things because you feel that you have to" she continues. "I hate collecting money and sometimes I would prefer to have a bit of free time instead of running a Church stall. Making time for oneself is important. When a child is ill everything becomes centred around the child. Mum is pushed to the back of the queue. Making time for oneself and one's marriage is important. I have come across parents who use part of their Attendance Allowance to buy in a baby-sitter in order to have time for each other.

"When a child is diagnosed as being disabled Mum has no option but to cope—she can't pretend that the situation does not exist. Men often feel more comfortable at work where they can forget what is happening at home. Gradually you find that the man is spending more and more time doing over-time. This is partly out of necessity as disability equals the need for mo[illegible] money, but also because it is convenien[illegible] It is important not to fall into this trap. My husband Stewart and I try to find time for ourselves away from the children.

"It might sound sexist but little girls are allowed to cry as they grow up and little boys are taught to swallow their emotions. Therefore, men often find it more difficult to express themselves in words and need time to communicate.

"Grandparents also need time to adjust. Many have dreamed of enjoying a problem free old-age with a grandchild. Suddenly their dream is shattered and many need support to come to terms with the reality of having a disabled grandchild. Naturally one should not generalise and some grandparents are very supportive from the start, others walk away.

"Able-bodied brothers and sisters als[illegible] need time. It is easy to forget to give the[illegible] attention, to go to their open days or take an interest in their hobbies.

"It is also important to try and find ways in which the disabled child can compensate for his or her disability, so that they do not become labelled as the coughing child or the wheelchair child. For example, one of my sons enjoys gymnastics and learnt to walk on his hands. In fact he developed such a reputation for this activity that when he arrived at his new school everyone knew of him. Likewise, I know a young boy with spina bifida who acquired a number of friends through a CB radio. They got to know him first and then became acquainted with his disability.

"I also believe in giving a child whether disabled or the sibling of a disabled child, the option to talk over their feelings with someone outside the immediate family. Friends, teachers, psycho-analysts all have a role to play. For example, my sons who have cystic fibrosis found it very valuable to go on holiday last year with a group of children who have the same condition."

Diana and her husband have acted as foster-parents to a number of children whilst offering respite care to others. In this book she looks at the emotional implications of placing a child in care.

"It is probably easier for a parent who feels he or she cannot cope to place their child in residential care than put him or her up for fostering. In a way what they are saying is 'I cannot cope and therefore no-one can cope with this child.' By placing the child in a foster-home one is psychologically saying is 'I cannot cope but someone else can.' The most soul-searching exercise is to admit that you would like to have your child adopted. In fact we have adopted a little girl and we keep in contact with her natural mother. I feel that it is happier for the child. It is possible for a child to love both its real and adopted parents."

In short, Diana's practical, refreshing, approach can only be an inspiration to others. She cannot offer solutions, but her book offers common-sense advice and should give parents the knowledge that they do not stand alone—that their feelings are natural and are shared and understood by others.

A Special Child in the Family is published by Sheldon Press and should be available from most bookshops price £5.95. In case of difficulty the mail order address is SPCK Bookshop, 36 Steep Hill, Lincoln LN2 1LU

SOLEMATES

Solemates is the brain-child of Ann Cross, a mother from Chingford. When Ann first found out that her son, who is now 22 years of age, had odd-sized feet, she thought that they were the only family to be confronted with such problems.

Today Ann runs Solemates on a shoe-string from her home. Up until recently Ann has given any profit to a charity, but she is now saving up to buy a computer for the 3,000 people who are registered with her.

"All my clients have odd-sized feet and want to spare themselves the expense of paying for two pairs of shoes every time they want new ones. It is not just a case of finding someone whose shoe size corresponds to his or her own so they can buy two pairs of shoes between them. It is a case of finding people who have the same style and needs in their footwear. Some people can't grip with their toes, others need shoes with buckles or straps.

I had a lovely letter from one lady who is 75 and does not want 'old-ladies' shoes. I thought that was great. I also have people on my books who have, for example, spina bifida. When a mother says her child's feet are very chubby, I know exactly what she means".

Ann is also able to supply names and addresses of manufacturers who, for example, specialise in shoes of two different sizes. She likes people to write to her, so that she has time to research their needs. "You would be surprised how many doctors and chiropodists refer people to me. I have no medical experience, just common-sense built up of years of looking at shoes," she laughs.

Ann spends three hours every day answering correspondence, and occasionally selling shoes which she has hidden in a bedroom, under the kitchen sink or indeed in any spare corner she can find.

"Once I have put people in contact with one another, it is up to them how they proceed. Some share the cost of buying shoes between them, others shop together or do it all by correspondence. Some soul-mates have struck up friendships and even spend holidays together."

Ann also looks after people who have had to have one leg amputated. "A man in his sixties who joined Solemates 10 years ago when he had a leg amputated has got by on slippers. Last week he called to see whether I could find him a smart black leather shoe, because he was getting married. Even people with quite small differences in their shoe size sometimes think they are monsters that everybody's going to laugh at, but they are not, and I tell them so," Ann concludes.

Life-time subscription to Solemates costs £3.00. Shoes bought direct from Ann cost approximately £5.00.

Solemates, 46 Gordon Road, Chingford, London E4 6BU. Please send a stamped addressed envelope.

CONTINUING ACTION ON INCONTINENCE SERVICE

The issue of the growing discrepancies in the incontinence service have been given Parliamentary coverage during the Committee Stage of the NHS and Community Care Bill.

An amendment was moved by Baroness Masham of Ilton that would require a district health authority to provide a district-wide incontinence service, and to identify an incontinence adviser and a consultant to take a special interest in incontinence. Lady Masham, moving the amendment, said it was becoming increasingly evident that cutbacks were being made in many districts and the amendment was necessary to prevent a continuous decline in the provision of incontinence services. She pointed out that cutbacks were detrimental to good community care provisions and that a failure to provide appropriately for a person's needs could lead to the development of pressure sores, costing millions of pounds to treat with hospital care. She was concerned that under the Government's proposals the responsibility for the matter might be moved from health to social services, fall through the middle and be lost altogether.

The amendment was supported by a number of peers. Baroness Cox said that incontinence was a serious social problem which required skilled assistance if physical problems such as pressure sores and infections were going to be avoided and if psycho-social problems such as loss of self-esteem, embarrassment, withdrawal and isolation were to be averted.

There would be increasing numbers of incontinent people and it was important to ensure that there were specially trained and identifiable staff in charge of arrangements for community care.

Lord Rea worked as a doctor in a district which established a uro-dynamic clinic which made, he said, a tremendous difference to the dignity of the lives of a number of people in his practice. He felt it was difficult for a GP to deal with the problem of an incontinent person and it needed a specially trained nurse to do so.

Baroness D'Arcy de Knayth strongly supported the amendment and said she had heard of circumstances where people were being told that their attendance allowance should be used to pay for incontinence pads. This was totally unacceptable and the Government should make it clear that that was not the purpose of the allowance. She also believed that continence advisers should undergo specialist training and their role should be upgraded.

Baroness Blatch, replying for the Government, said the Government recognised the importance of the issues raised. She pointed out that there was already a health notice which gave advice to the planning services authorities in the provision of a district wide incontinence service. However, the Government believed that as in other areas of health care provision, district health care authorities should be left free to determine the pattern and level of services in their districts in the light of local needs and circumstances. She believed it was important that one of the advantages of the new system as proposed under the Bill was that health authorities would have to publish plans to meet the needs of the community, and this would help ensure that adequate resources were made available for incontinence services.

Lady Masham withdrew the amendment but made it clear that she believed that the organisations involved in promoting the amendment would wish to have a provision written into the Bill.

ASBAH, as one of those organisations, will continue to press the issue and we hope we can look forward to the time when we see a genuine improvement in the provision of incontinence services.

SANITARY PROVISION FOR SPECIAL NEEDS

by Dominique Cull, ASBAH's Accommodation Officer

Research on sanitary provision for people with special needs has been commissioned by the Department of the Environment.

The aim is to produce data on user needs, to be used in the possible issuing of comprehensive guidance on the planning and design of public lavatories and toilets in public buildings.

The British Market Research Bureau is conducting personal interviews in Carlisle, Eastbourne, Hereford, Peterborough, Swindon, Telford and possibly one or two other towns. The results should be known by November.

The task will be to obtain information on usage in different types of public buildings to examine the extent to which people can be handicapped by the lack of suitable provision and to indicate what practical provision might best satisfy varying needs.

Requirements being checked include: level access, avoiding steps or stairs; wheelchair or pushchair access through lobby doors and within WC compartments; 'unisex' facilities, e.g. for a wife helped by a husband; space requirements for wheelchair transfer; WC height and alarm-call requirements.

This project is an opportunity for people with disabilities to state what facilities they need, instead of relying on the chance that the architect will get it right. It is research which ASBAH feels has been long overdue, looks forward to seeing the results and, hopefully, the issue of comprehensive design guidance.

NEWS ROUND UP

Gait for Ricky

Ricky Cumberbatch

Two year old Ricky Cumberbatch from Barnsley in Yorkshire is one of the youngest children in this country to have a Reciprocal Gait Orthoeia. Ricky will never be able to walk on his own but with enough strength in his upper limbs to maintain his balance, he can benefit from this brace.

Major Increase in Disabled Student's Allowance

The Secretary of State for Education has announced a major increase in Disabled Students' Allowance which will come into effect from September 1990. From that time the maximum general Allowance will rise to £1,000.

In addition two further Allowances will be introduced: one for non-medical personal helpers, such an interpreters for the deaf, up to a maximum of £4,000 a year, and the other for major items of specialist equipment, like word processors with braille printers, up to a maximum of £3,000 spread over a whole course.

The Government has also announced that disabled graduates will not have benefits included in the calculation of their income in order to decide when repayment of loans should begin. Furthermore, as students, they will continue to receive benefits when eligible, unlike other students.

Skill, the National Bureau for Students with Disabilities, has been working closely with other voluntary organisations, including the RNIB, RNID and RADAR to try to ensure that particular financial needs of disabled students in higher education were taken into account as the Education (Student Loans) Bill passed through Parliament.

Duke of Edinburgh Award Success

18 year old Deborah Hallas and 20 year old Ann Murray have both won Duke of Edinburgh Gold Awards which were presented to them by Prince Philip at St James's Palace in London.

Deborah who was a young leader in the Guides, played wheelchair hockey and did needlecraft for her skills.

Ann works for the regional health authority in Bury St Edmunds. She did horse-riding, tapestry and raised funds for the Red Cross.

They both went to Holland to study windmills for their expedition and stayed away from home on the island of Jersey.

Disability Rights Handbook

The 15th edition of the Disability Rights Handbook, a unique guide to rights, benefits, and services for all people with disabilities and their families has just been published.

Among other special features and a wealth of practical advice, the new edition contains detailed coverage of current and forthcoming social security provision for people with disabilities. As Government proposals for benefit changes announced earlier this year seem set to add to existing complexity and confusion, the Disability Rights Handbook provides comprehensive and easy-to-use guidance through this difficult field.

Whether you are one of the 4.3 million disabled people in this country who depend on benefits—or one of the millions more who might be entitled to benefits—or are personally or professionally involved with a disabled person, you need up-to-date information to make sure that you, your friends or your clients do not get confused or left behind and out of pocket.

The Disability Rights Handbook is available from:

Disability Alliance E.R.A.,
25 Denmark Street,
London WC2 8NJ.

price £4.00 post free. Allow 28 days for delivery.

New WELLCOME Trustee

The Wellcome Trust is one of Europe's largest medical research charities devoted to general medical research and the history of medicine. In 1988/89 it spent approximately £44 million in universities, medical schools and research units throughout the world.

The Wellcome Trustees have invited Professor Sir Hans Kornberg ScD, Hon. FRCP, FRS, to become a Trustee from 1 October 1990.

He will succeed Dr I Helen Muir who retires as a Trustee at the end of September 1990.

Sir Hans was a student of the late Sir Hans Krebs at the University of Sheffield and was a colleague of his in the University of Oxford. He was appointed to the Chair of Biochemistry at the University of Leicester in 1960 and, in 1975, to his present post as the Sir William Dunn Professor of Biochemistry in the University of Cambridge. Since 1982, he has also been Master of Christ's College, Cambridge.

Sir Hans is noted for his studies of the metabolism of 2-carbon compounds in micro-organisms which led to the discovery of the glyoxylate cycle (a metabolic route that explains also how plants convert fatty acids to sugars) and to the formulation of the concept of 'anaplerotic' enzymes. More recently, he has been distinguished for his studies on sugar transport in micro-organisms.

HYDROCEPHALUS AWARENESS CAMPAIGN

On June 11th ASBAH will launch a nationwide campaign to help make professionals, employers and the general public aware of the problems of hydrocephalus. This date will coincide with ASBAH's move to new head-office premises in Peterborough.

Hydrocephalus is caused by an imbalance between the production and absorption of cerebro-spinal fluid which results in the swelling of the ventricles (cavities) in the brain. The pressure caused by this blockage has to be relieved speedily, in order to minimise any damage. This is usually done by the insertion of a valve which drains the excess fluid into the abdominal or heart cavities. More than 85% of people with spina bifida may also have hydrocephalus but it is also a condition which can occur independently.

Hydrocephalus is very much a 'hidden handicap'. People with the condition can often walk and may look as able as anyone else. By not appearing 'different' it is often much harder for them to be accepted as having a disability by their peers, tutors and employers.

The degree of disability arising from hydrocephalus can vary enormously. People with hydrocephalus may be unable to sustain long periods of concentration on a particular task; they may be easily distracted, having difficulty in focussing their attention on the task in hand. Short-term memory is another problem. People with hydrocephalus are often unable to cope with pressure whilst lack of eye/hand co-ordination can lead to difficulty in using equipment such as a stapler.

Perhaps this short list will offer some insight into the effort someone with hydrocephalus has to put into fulfilling some of the day-to-day tasks which most people take for granted.

The Association for Spina Bifida and Hydrocephalus is confident that once teachers, parents and other professionals become more aware of the obstacles which a person with hydrocephalus has to conquer, they can help them to plan for a fulfilled life. Leonie Holgate, a Disabled Living Advisor at ASBAH is aware that with the right strategies, young people with hydrocephalus can often achieve good academic results and become valued employees.

Leonie Holgate has been involved for a number of years with families and individuals with hydrocephalus. She has found that, until the age of about 5, a young child will occasionally be accepted by his or her peer group. After that time the child with hydrocephalus will continue to develop but at a much slower pace than other children. This can lead to isolation and it is not unknown in a typical playground scene to find a child with hydrocephalus standing alone.

Parents, teachers, employers and other professionals all have a role to play if a young person with hydrocephalus is to be encouraged to gain independence and maturity. It is easy to believe that a young person with hydrocephalus is not trying to achieve, without fully comprehending the effort needed to undertake simple tasks.

Hydrocephalus is a 'hidden handicap'... by not appearing 'different' it is harder to be accepted as having a disability ...

ASBAH is a great believer in a structured approach to life. It's aim is to help people identify problems and then find simple solutions. If a person finds it difficult to memorize something they have read, encourage them to read it out aloud or better still, talk about it. Use tape recorders and other modern aids. If new surroundings leave someone bewildered, find a friend to meet them at the door and act as a companion. Plan each task individually and when it has been achieved, go on to something else.

For most of us, it is quite reasonable to presume that we might go to the bank to sort out our finances, tackle the laundry, cook an evening meal and wash our hair all on the same day. For someone with hydrocephalus, planning just one of those tasks may take an entire day. Just writing out a time-table can be a great help.

Unfortunately, because many people do not fully understand the hidden handicaps associated with hydrocephalus, it is very easy for someone to be dismissed as being frustrating and not really interested in learning, when that is far from the truth.

It is not only at school that they can be discriminated against, but later on employers can have unrealistic expectations through ignorance. Given the right support a person with hydrocephalus can become a valued member of a team.

18 year old Victoria Treloare lives in Cornwall and left school with 8 '0' levels. She then went on a YTS course at the local Electricity Board. Victoria wrote to several employers seeking full-time employment and was taken on by a major high street bank. Although the Bank was aware of her disability, they placed her on the same training course as any other able- bodied employee. During her training period problems were raised during her appraisals regarding her output of work and her ability to learn new tasks. "I could feel things going wrong" Victoria explains. "I find it very difficult to concentrate for long periods of time. I need short breaks. The more someone pressurizes me the more I go to pieces. Pressure is about the worst thing for someone with hydrocephalus".

The Bank tried to accommodate Victoria and created a new post which consisted of answering the telephone and sending out the post. "Here again I found it difficult to be able to talk to a client on the phone and also listen to instructions someone was shouting at me in the office at the same time. I tried to explain to them that I can only do one thing at a time. There are also days when I could get the post out at an average speed, but there were also days when it took me longer to get the letters into the envelopes. It all depends on how well my shunt is working as to how co-ordinated I can be".

The day before Victoria was due to go into hospital for treatment, the Bank wrote to her at home stating that they no longer required her services. "I was heart-broken, I really wanted to work. I had taken leaflets written by ASBAH in to the Manager in the hope that he would understand my disability. On the surface he appeared to be sympathetic, but at the same time, he expected me to finish set tasks in an allocated time, which was impossible for me."

It was at this stage that ASBAH became involved. An ASBAH Fieldworker and ASBAH's Education, Training and Employment Coordinator liaised with the Bank's union representative and decided to appeal against the Bank's decision. The Bank was very understanding at the appeal. Victoria was reinstated at another Branch under a Sheltered Placement Scheme. A Branch, which consists of only 12 people was selected for its size and everyone was briefed as to the problems which can occur in instances of hydrocephalus.

Victoria is now carrying out normal banking duties and is delighted to feel settled and at ease whilst also able to undertake a variety of daily tasks. "Now I do not try to over-stretch myself. I avoid all pressure and ask for help when I need it", Victoria concludes.

Victoria receives instructions in a concise, regular pattern and one person acts as her supervisor in order to offer her advice and support. The Bank are aware that they can call upon ASBAH for guidance and information. Victoria is adamant that her presence in the Bank helps other people realise what life is like for someone with a disability.

ASBAH is always willing to support teachers, employers and other professionals. Personal contact can be made with our Fieldwork Manager or Education, Training and Employment Coordinator. A series of fact sheets have been published including 'What is Hydrocephalus' and 'Notes for Employers'. These are available from the Association for Spina Bifida and Hydrocephalus, ASBAH House, 42 Park Road, Peterborough PE1 2UD.

STOP PRESS STOP PRESS STOP PRESS STOP PRESS

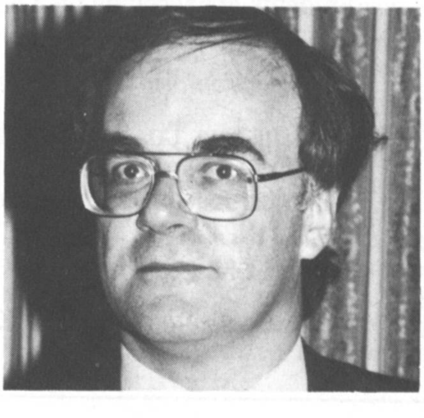
NEW ASBAH ADDRESS
From June 11th 1990 The Association for Spina Bifida and Hydrocephalus will be moving to:
ASBAH HOUSE 42 PARK ROAD PETERBOROUGH PE1 2UD,
TEL: 0733 555988.

New Publicity Manager

42 year old Tony Britton (pictured right) has been appointed Publicity Manager for the Association for Spina Bifida and Hydrocephalus.

To date Tony has spent fourteen years with Thomson Regional News in Peterborough where he was the News Editor.

He is joined by Jill Winfield whose career has included working as Assistant Editor on John Lewis Partnership's staff magazine.



THE NHS AND COMMUNITY CARE BILL

The NHS and Community Care Bill continues its progress through the Parliamentary system. Generally, the Government has been most reluctant to write changes into it, arguing that the Bill should be a facilitator rather than a straight jacket. The Social Services Inspectorate are producing draft guidance notes on the principal areas of change in community care—those are the drawing up of local Community Care plans, care management and assessment, inspection and quality assurance, purchasing and budgeting, mental illness, training and complaints. The voluntary sector is making an input into each of those project groups and it appears that formal draft guidance will be issued for wider consultation in June, to be finalised for the autumn. The final codes of practice are expected to be issued in December and these should flesh out the bare bones provided by the Bill itself.

Many people believe that it is not sufficient to rely on guidance notes, as hard pressed local authorities attempt to allocate resources to cover their wide range of responsibilities. There is, therefore, continuing pressure in Parliament to amend the Bill to provide, at the very least, a few more bare bones than there are at present.

In the last copy of *Link* we outlined some of the commitments given by the Government. In this issue we update progress on the Bill, the only real addition being a requirement for local authorities to consult the various other authorities in drawing up their community care plans.

Since writing the last article there has been very little Parliamentary discussion on the Community Care part of the Bill in the Commons, but during Report Time, an amendment was accepted to the Bill, which was not debated, that requires a local authority to consult the following organisations in drawing up their community care plans:

(a) Any district health authority which lies within the area of the health authority;

(b) Any Family Health Services Authority whose locality lie[illegible] within the area of the local authorities;

(c) In so far as any plan may be affected by the provision or availability of housing, every local housing authority whose area is within the area of the local authority;

(d) Such voluntary housing agencies and other bodies as appear to the local authority to provide housing or community care services in their area;

(e) Such other persons as the Secretary of State may direct.

The glaring omission is that of consumers and disabled people themselves. Disability organisations will continue to press for their inclusion and are hopeful for success given the commitment by Virginia Bottomley during the Committee Stage in the House of Commons.

Implementation of Disabled Persons Act

The Government has announced that it is consulting on implementation of Sections 1, 2 and 3 of the Disabled Persons Act. Section 1 gives disabled persons a right to have an authorised representative who can act on their behalf or with the disabled person in their negotiations with the local authority fo[illegible] their assessment. Section 2 lays down the rights of the authorised representative, which are similar to those of a disabled person, and Section 3 gives disabled people the right during the assessment process a) to make representations concerning their needs and to have their views taken into account, b) to a written statement of the outcome of the assessment and c) a right of review against the outcome of the assessment.

These sections of the Act are critical to the implementation of a genuine consumer-led community care service and ACT NOW have been pressing for full implementation of the Act since 1986. It believes the remaining section of the Act must be implemented to make real sense of the Government's proposed community care proposals.

Lobbying has been continuing at a national level and it is felt that this should be supported by lobbying from a local level. It has asked its member organisations and disabled people to write to the Minister concerned, expressing the importance of full implementation of the Act.

Anyone wishing to write should address the correspondence to Virginia Bottomley M.P., Minister of State for Health, Department of Health and Social Security, Richmond House, 79 Whitehall, London SW1A 2NS.

NEVER GIVE UP HOPE—THE STORY OF JOE

"You are not alone, things are not as bad as they appear", is the one message Cilla North would like to offer to other mothers whose children have been born with spina bifida.

For 33 year-old Cilla from Haringey the birth of her son Joe three years ago meant a time of re-adjusting. "I had known something was wrong before he was born, you might call it a mother's instinct, but no one would believe me. Once I knew that he had spina bifida, I never gave up hope. Sometimes it felt like me against all the medics.

"When Joe was born the doctors told me that he might not live and if he did his prospects would be bleak. I just pushed those thoughts out of my mind. I did not want to hear such words of doom. In fact, the only person who offered me any hope was ASBAH's fieldworker. It took the doctors 4 days to decide to stitch up Joe's back. I couldn't be put off even when he developed meningitis, as my older son Harry had had that; I just told them to give him antibiotics".

During that time Cilla read a lot of medical books in the library. "I knew that spina bifida existed but I knew nothing about it. An orthopaedic surgeon told me that Joe would be in a wheel-chair by the time he reaches his teens, but at the moment he is walking around with sticks or callipers. The only thing he cannot do alone is go to the toilet.

"It is difficult to get a child minder who is prepared to catheterise him. Even his grandparents are scared of doing that for him. People are so squeamish, or is it that they feel such duties sacred and they might make a mistake—I don't know". Cilla envisages problems when Joe starts Nursery School as she is not convinced that the school will be able to find, or afford to pay for a carer to help him with his personal tasks.

People's attitude to disability also annoys Cilla: "Once the doctors told me Joe was going to be disabled, it felt as if they were telling me that he was not going to be a valuable member of society. When we are walking along the street, people will rush up to Joe as they see him with his callipers and compliment him on being a brave boy. It makes me so angry, as I see him as normal".

"I think the most valuable thing you can offer a child with disabilities is some sense of a future. I have always pushed Joe, shown him new ways of doing things and kept him motivated. The physiotherapists are the most constructive people, if they can't find one way of encouraging him, they will find another way. One of them taught me how to roll up a towel under his arm-pits in order to teach him how to crawl. You have to be inventive", she laughs.

Like most families Cilla is aware of a strain on the marriage. "One of the problems is finding people to give you that break, that night out away from the children. My husband enjoys Harry our first son more because he is now 6 years of age and can respond. From what I can understand, most men are not that keen on babies. I guess any ups and downs we have are also partly my fault as I like to take control, know all the facts and make decisions.

"I have taken Joe to hospital so many times and on occasions I have needed to decide whether or not to go ahead with yet another operation. His hips were dislocated and his legs needed twisting around. A year later the pins had to be taken out. Now he needs an operation to find a missing testicle, although that is a common complaint and nothing to do with spina bifida.

"Sure, there has been sibling jealousy, but that is normal. I have always told Harry that Joe is a special child with special needs and that he is special by just being Harry. They fight and throw things at each other like other children. I do not think that Joe is aware of his disability. I guess he will find that out when he gets to school. I am going to wait until he asks questions before I explain anything. At the moment he treats his disability as normal. Joe does not appear to be backward, in fact he has passed all his development tests. He started talking a little late, but often second children do that. They can afford to be lazy, they have a brother or sister to do it for them.

"It is difficult to find suitable clothes. I used to knit madly to make socks for Joe's cold feet. Now I have found a shop in Amsterdam where they make inexpensive sheep-skin boots. Clothes which are extra thick are essential; man-made fibres don't absorb perspiration."

Cilla is concerned that not enough information is available for parents when their child is first diagnosed. "I guess though that it is a bit like life generally, you don't always know what you want to know until it is too late."

AMNIOCENTESIS—A LONG TERM AFFECT ON CHILDREN?

A woman who has fluid removed from the womb while pregnant—in the procedure known as amniocentesis—may increase the risk that her child develops ear problems according to Jo-Anne Finegan and a team of researchers at the Hospital for Sick Children in Toronto.

Amniocentesis is usually performed when a woman is at a greater than normal risk of having a baby with a serious disorder. The woman has the test about 16 weeks into her pregnancy.

Doctors use ultrasound to guide a needle through the abdomen and into the womb. They draw out a small quantity of fluid—about 20 millilitres or so—and make a diagnosis by chemical or chromosomal analysis.

When amniocentesis, which can detect spina bifida and Down's Syndrome, was introduced more than two decades ago, there were a number of major trials to discover whether the procedure had any adverse effects. Most of the trials concentrated on problems that might arise in the pregnancy, during the birth and in the child's first 12 months. The research in Toronto has looked at children up until the age of 4 years. (British Journal of Obstetrics and Gynaecology, Vol 971 p32.)

...mothers who had undergone amniocentesis were more likely to report a history of ear infections in their child.

The earlier studies found that amniocentesis is not without risk. The test causes about one per cent of pregnancies to abort. Also this group of children are more likely to have breathing problems during their first days.

In the trials in Toronto, 134 pregnant woman aged between 35 and 40 were tested. Of the sample, 88 opted for amniocentesis. When the children reached the age of four, Finegan's team gave them a number of intelligence, behavioural and development tests. They found that both groups—those whose mothers had undergone amniocentesis and those whose mothers had not—had similar results. But they discovered that mothers who had undergone amniocentesis were more likely to report a history of ear infections in their child. According to Finegan, this type of result is notoriously unreliable. But when she and her colleagues found differences in the way the ear responded to sound between the two groups, they began to take the mothers' reports seriously.

They tested the compliance, or stiffness, of the eardrum, by measuring the sound energy reflected by it at different pressures in the ear. Children in the amniocentesis group were more than three times as likely to have abnormal readings. However, the changes were subtle—none of the children had measurable loss of hearing. The researchers put these variations down to the disruption of the delicate balance of pressure across the eardrum, preventing the drum from vibrating normally. The Eustachian tube and the structures within the fetal ear form during the second trimester. "It is possible", says Finegan "that pressure changes, caused when fluid is lost during amniocentesis, may perturb development".

The researchers excluded another possible factor that could have affected the children: ultrasound scans carried out on their mothers during pregnancy. The children's eardrums had similar levels of stiffness, whether or not their mothers had received ultrasound scans.

But Finegan's anatomical view does not find favour with all of the researchers. The factor most likely to affect pressure across the eardrum is the state of the Eustachian tube. Infections cause it to fill with liquid, which stops pressure changing behind the drum.

"The problems did clear in time ... which tends to discount an anatomical point of view."

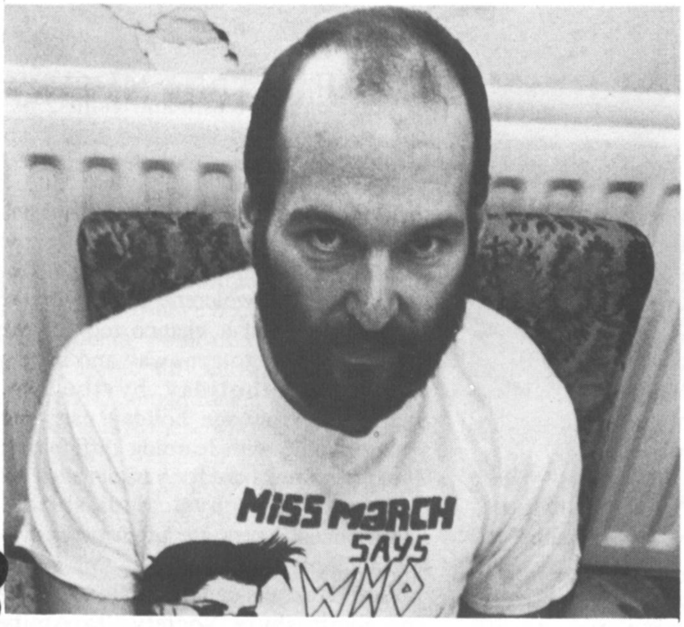
Marilyn Boydon, chief audiologist of the Toronto Study, says that the children in the amniocentesis group may have been exposed to more infections after birth, leading to impaired ear function, but she said that more trials are needed to explain why. The children were all recalled to her clinic. "The problems did clear in time", says Boydon, "which tends to discount an anatomical point of view." Nevertheless, in a published paper, the researchers discount these environmental factors.

In Britain, Sir Alec Turnbull, the Chairman of a working party on amniocentesis which was set up by the Medical Research Council, says the study is 'intriguing'. He said he expected it to arouse a whole set of new trials.

At present, the only alternative to amniocentesis is chorionic villus sampling, or CVS, during which a tiny piece of the development placenta is removed for genetic testing. This procedure causes a slightly higher rate of aborted pregnancies than amniocentesis. But, says Turnbull, "the new results may be an argument for CVS".

by Jeremy Webb with kind permission of the New Scientist

THE SPIRAL CAGE



One of the publishing sensations of the year has been *The Spiral Cage*, Al Davison's graphic autobiography—an adult comic book revealing his triumph against all the odds over severe spina bifida.

The book thinks the unthinkable, and Al draws it in page after page of mind-searing detail, with no attempt to draw a veil over even the most intimate of human contacts. Anything less, one senses, would have trivialised the Al Davison story, and have been of little use to the author on his journey of self-discovery. He was born severely injured, and every stage of development since has been a battle, which he seems to be winning.

This remarkable life of an extraordinary man begins with Al acknowledging his debt to his parents, who insisted that the medical profession gave their son his first chance in life.

"He is literally a hopeless case. This is not meaning to sound defeatist, but there is little hope." the doctor noted after he was born. "His parents are adamant, however, to proceed, no matter what, against my advice, so we must do what we can... "

Today, 30 years and 21 major operations later, Al is a skilled martial artist, an avowed Bhuddist, and he works in the performing arts in his home city of Newcastle. He lives with Maggie, and success with the autobiography will probably provide the launchpad for another seven books buzzing around in his head and on the drawing board. "You know, your average vegetable!"

The Spiral Cage is named after the shape of that microscopic bit of life-building material, DNA. Al says he has broken out of his internal trap, and externalised the process by rejecting callipers and sticks.

The book tackles subjects like prejudice, pain, adolescence and the sheer optimism of the little boy who believed "everybody lives in hospital 'till they have lots of operations so they can walk."

The Spiral Cage, by Al Davison, is published by Titan Books at £5.95.

HOLIDAY, TRAVEL AND SPORT

SWIMMING FOR GOLD

Sarah Redman

16 year old Sarah Redman has recently returned from America with two gold and two silver medals won for swimming at the Olympic Paraplegic Games, in Miami. Fifteen nations took part in the games. Sarah won the gold in the 25-metre and 50-metre freestyle events and silver in the 25-metre backstoke and 100-metre freestyle races.

Sarah started swimming at the age of 6 and she is at present on work experience in order to fulfil her ambition to become a swimming teacher."I feel free in the water. That is why I enjoy swimming so much. Disability does not matter at all" she concludes. Sarah is now in training for the 1992 games in Spain.

A HOLIDAY AT HOVE

Walsingham House, an adapted Edwardian house, a 2-minute wheelchair ride from the Hove Seafront, has been used as a holiday home for young disabled holiday makers since 1970, when there was seen to be a need for accommodation for school children who had no families to go home to during the summer holidays. At the end of 1988 the Trustees asked The Shaftesbury Society to manage it, whilst still maintaining its original use. The Shaftesbury Society is a national charity, well known for its educational establishments and residential care homes for physically disabled people and those with learning difficulties. It welcomed the opportunity to provide this much needed provision along with its other 2 holiday centres— one specialising in holidays for elderly disabled people and the other providing low cost self-catering accommodation for young peoples' groups.

"We've all had a lovely week—we'll be back." "We've had a really good time— super facilities, thanks again."

These are the comments and many more that we have received since taking over Walsingham House holiday home. Meg Thomson recalls some lasting memories of her first few months as the Officer-in-Charge:

Natashe and Maxine laughing, holding hands, careering at a breakneck speed in their wheelchairs along the prom (beware unsuspecting promenaders!). Phil, Mike, Gary and Rob, Meg's husband, playing bowls in the back garden—the concentration on Mary's face! Helen, aged 10 with a mental age of 3, deciding it was fun to stuff a tissue into the plug and leave the water running. Tony, expertly making scrambled eggs for 9, wheeling from the microwave to the table for each 30-second stir and the look of sheer delight as we all tucked in.

Then there were the trips out; ducks, goats and kids (of the goat variety) eating out of our hands at Bentley Wildfowl Trust; stock car racing at Arlington; the snowballs and chocolate fudge cake at the Black Rabbit in Arundale and barbecues; and the amazing sight of Gary doing his ghost act from the front bedroom window as we returned home from our midnight walk to Brighton. Apparently, he had been sitting there for at least an hour, with a sheet over his head, making noises at anyone who happened to be passing!

Walsingham House provides 2 types of holiday for disabled young people. Firstly, self-catering accommodation the whole year round, from a family with one disabled member to a maximum of 8 disabled guests plus accommodation for over eight helpers. The disabled holiday maker brings his or her own helper, but no charge is made for these helpers.

Secondly, during the summer period, the Shaftesbury Society arranges holiday parties at the House, organising the helpers and a leader for each week. This gives an often welcome respite to the usual carers and a chance too for the disabled person to get away and have a really good holiday by the sea. Shaftesbury run one holiday party for young people with learning difficulties. The other weeks are for various ages for people with a physical disability. Experienced carers are often needed to lead such parties.

Further details can be obtained from:- The Shaftesbury Society, 2a Amity Grove, Raynes Park, London SW19 OLH Tel: 081-946 6635.

HAPPY MOTORING

Learning to drive is no easy option for anybody, given the state of the roads, but it is an activity which ASBAH manages supremely well at its Five Oaks independence training centre in Yorkshire—in a course uniquely tailored to the needs of people with spina bifida and/or hydrocephalus.

ASBAH's 10th course in 5 years took place at the end of April, and with seven students it was also the largest group so far. Course members travelled from as far away as Dublin and Bude in Cornwall for five days intensive coaching in getting them ready for the road.

The pre-course get-together turned into quite a party with Five Oaks manager, Joan Pheasant, organising an anniversary cake, decorated with 'Happy Motoring' and four small cars. Then it was down to business, with the first two days spent off-road on the immense parade ground at the Army Apprentices' Barracks in Harrogate.

The remaining three days were spent either in the classroom at Five Oaks, with two lessons on-the-road each day on the hills around Ben Rhydding or mixing with town traffic in nearby Ilkley.

Course tutor, Leonie Holgate, said the strength of the course was its intense structuring to suit the needs of each individual, and the quality of the teaching team support. On this last occasion, Leonie was joined by Chris Beynon, who helped set up the course, two local driving instructors, Malcolm Kleiman and Dennis Sutcliffe who specialise in teaching the disabled, and a psychologist from the Banstead Place Mobility Centre in Surrey, Barbara Simms.

The driving course is for people who already hold a provisional licence, and preferably their aptitude for motoring should already have been assessed. From the Students' point of view, it is worth saving up mobility allowances to try for the course, though financial support may be available to those who need it. It is also advisable to obtain a suitably modified car as quickly as possible so that skills learnt on the course can be practised and retained.

(Details about future courses from: The Five Oaks Centre, Ben Rhydding Drive, Ilkley, West Yorkshire, LS29 8BD (tel: 0943 603013)

LES LEAVES THE FIELD (see photograph right)

Staunch ASBAH supporter Les Langan (second left) hung up his boots in fine fashion when he organised his annual soccer match for us a the end of April.

Les has collected £20,000 for ASBAH since he and Post Office colleagues at London's Liverpool Street Station held their first charity game 18 years ago; he became involved following the death of his first child who was born with spina bifida.

To mark his retirement from work in September—and his departure from playing status—his team entertained a celebrity team of sports commentators and soccer professionals at the London Postal Region's sports ground at Blackheath. We draw a veil over their crushing defeat on the field, except to quote a breathless Les who said: "It didn't really matter who won out there. The real winners were ASBAH."

Les is pictured, from the left, with former Luton Town manager, and now Wimbledon coach, Ray Harford, ex-Spurs player Joe Kinnear, who is now Wimbledon's reserve team manager, and referee Ted Ellis. Athletics commentator, Alan Parry, is kneeling. (Photograph: Paul Willatts)

THE DRIVE FOR INDEPENDENCE

Ford have just produced a new video called "I'll Drive" which traces the progress of seven people, all of whom have restricted mobility.

The video illustrates their commitment and determination to drive and, through their own personal stories, provides valuable information on mobility assistance programmes, assessment centres and the variety of innovative vehicle adaptations which have helped them to drive and gain greater independence.

Educational and informative, the 33 minute production is designed to provide encouragement for disabled people who wish to drive. But it does not gloss over the difficulties. Attention is drawn to the need for professional assessment and instruction of new disabled drivers and to the time and costs involved

Secretaries of clubs for the disabled and other interested organisations can obtain a VHS copy of the video on free loan from Ford by applying to Freepost Ford, London W1E 8EZ

EASIER RAIL TRAVEL

British Rail has produced a video to show how rail travel is being made easier for customers with mobility problems. The film, entitled 'In Good Hands', is being distributed to organisations representing disabled people. Principal stations throughout the country have been equipped to cater for the needs of customers with disabilities. Many new trains, designed to be readily accessible to all disabled people including those in wheelchairs, are now in service, and hundreds more are on order. The new video which is designed to highlight these developments and to encourage those with mobility problems to travel by train, is being shown to BR's staff. The video, which runs for 14 minutes, is available on request to Sheridan Hughes, Liaison Manager (Disabled Travellers), British Railways Board, Euston House, 24 Eversholt Street, London NW1 1DZ.

CONVERSATIONALIST OF THE YEAR

ASBAH's annual contest to find the Conversationalist of the Year took place on May 13th at the Glaziers' Hall in London. The event was sponsored by Whitaker's Almanack, Britain's most prestigious reference book.

The 26 contestants were bubbly and vivacious, and enjoyed talking on anything from pets to puddings. Contestants' interests varied enormously and teachers, underwriters, solicitors and PR executives enjoyed the challenge of mental sparring.

The three celebrity judges, Claire Rayner, Barry Cryer and Graeme Garden had a difficult task to choose the winner. They, like all the audience, thoroughly enjoyed the two finalists, 28-years old Angela Gordon, a video-tape editor, and 45-year old Jeremy Lee, a solicitor, who had to converse for an hour on 'The Games People Play'.

Whilst talking their way through from tennis and squash to horse racing and darts they also flirted and laughed with one another. Eventually, the judges decided that Jeremy Lee was to be awarded the prize of Conversationalist of the Year. "It was tremendously good fun, and one met some most delightful people. I talked to Angela earlier in the day and we got on very well, and so although an hour was a long time it actually was great fun."

Jeremy was surprised at winning the title as he consider himself to be a social wallflower and is conscious that his friend look on him as a bore. Jeremy comes from Crediton near Exete and used to be a member of the Royal Marines before becoming a solicitor. He wins a holiday for two in a villa in the Algarve in Portugal.

Photographs: Paul Loosley

**Left to right:
Angela Gordon, Graeme Garden,
Barry Cryer, Claire Rayner and Jeremy Lee**

The winner Jeremy Lee with Sally Whitaker, Managing Director of Whitakers and Moyna P. Gilbertson, Executive Director of ASBAH (right)

CARING FOR THE CARERS

With the NHS and Community Care Bill nearing completion in the autumn, disability organisations are pressing to make sure that not only the voice of the person with disabilities is heard, but also that of the carer. Crossroads Care recently undertook a survey of 1,000 carers. The questionnaire revealed that caring is a long arduous commitment—a 24 hour-a-day commitment with no relief. Most carers have little prospect of leading a 'normal social life'.

Voluntary organisations feel that Government and local authorities should recognise the commitment carers make and prioritize services to support them. Out of those carers questioned 54 per cent had given up employment, whilst 40 per cent would like to return to work. With present arrangements, if all those carers who wanted to return to work did so, the implications for local authorities would be enormous.

25 year old Claire Brotherton is a bubbly vivacious woman who would dearly love to follow a song and dance career on stage. In fact she won a contract to appear in Japan with the possibility of other exotic venues to follow. However, two years ago Claire's mother became very ill: infection after infection resulted in cancer of the bowel. Collapsing on one occasion, her mother went into a coma. A miracle happened and she came out of [illegible]" Claire explains, but it has meant that her mother has had to start from scratch by learning to eat, walk and talk again.

Claire decided to forget about a stage career or indeed to continue in the nursing profession for which she was qualified. Instead of a regular salary and the chance to save for a mortgage and a life of her own, Claire accepted £28.00 Invalid Care Allowance in order to care for her family. "It was my decision to stay at home to look after my mother and brother. I wanted to do it". Claire's brother Martin is 28 years old. He has spina bifida and hydrocephalus and needs daily attention. "For years my mother did everything for him on her own. I am quite sure that the pressure of caring resulted in her ill-health. It just all became too much. We did not have transport at the time. Every day mum had to walk home with incontinence pads, prescriptions or other nursing aids".

Today Claire plans her life and interests around the family. "I have lots of pen-friends and enjoy corresponding and I try to do some charity work, or help out at the local nursing home if they are short staffed. My mother needs help washing and dressing. Martin needs his urine expressing twice a day and his bowels need to be evacuated. It is just a matter of putting pressure on his stomach. It is very difficult to find people who are dedicated enough to take on such personal tasks. Even district nurses have told me that they are prepared to help wash and dress Martin, but they would rather not toilet him".

Claire sounds quite matter of fact about a routine of dressing weeping wounds, checking tablets and helping to build up her mother's confidence by encouraging her to take slow steps which often result in her being out of breath.

"I don't plan ahead—I am scared to" she states. One thing Claire does know is that she has taken on a life-long commitment to care for her brother. "As long as my mother is not well enough and after my parents have died, I will look after Martin. I would never put anyone I loved into a residential home. It would take away all their independence. Martin has a brain, he loves painting and artwork and spends hours on his computer. The main problem is that there are not enough clubs locally in Cheltenham for him to go to to meet other people".

It is not only Claire, but also her fiancé, Chris, of eight years standing, who is determined to continue the family unit. Although they have no plans to marry at present, if they were to do so, Martin would be invited to live with them. "It was actually through Martin that Chris and I met at the local Day Centre. I had gone there with Martin for a barbecue and Chris was one of the helpers. Like all men Chris does not like doing medical things, but he is a great support and he and Martin are good friends" Claire explains.

Claire has some input from local authority and voluntary organisations, although this does not always allow Chris and Claire a Friday night to themselves. "We work around the family, but people are supportive towards me." Claire is sad though that this recognition of the family's needs only came after her mother's health had crumbled to such an extent that a crisis had developed.

Crossroads survey revealed that carers feel neglected and unsupported. They would like to ask for regular assessment, guidance and counselling. They want more training for themselves and the professionals who support them. They want more flexibility in the services provided, more respite care and greater income so they can secure a reasonable standard of living.

This space donated by

ASTRA MEDITEC LTD

Manufacturers of the
self lubricating
catheter

LoFric

Who send to ASBAH best wishes for a successful year
"carry on the good work"

The simple way to put you in touch with the largest range of Ostomy & Incontinence Supplies

As one of the longest established companies to specialise in the supply of Ostomy and Incontinence appliances we are pleased to offer probably the largest range of products all under one roof.

All leading makes are stocked including ● Downs ● Hollister ● Coloplast ● Clinimed* ● Simpla ● Eschmann ● Franklin ● Bard ● Redland ● Dansac-Combi ● Thackray ● Salts ● Birkbeck ● Translet ● Squibb-Surgicare. All types of barrier creams, plasters and deodorants. ● Catheters, leg bags and night drainage bags.

We offer a friendly and professional service to private individuals, Pharmacists and Chemists.

All products are stored in temperature controlled conditions in our large modern warehouse. A permanent Display Showroom enables you to see the most up to date appliances and qualified staff are always available for expert advice and information.

National Health Service prescriptions dispensed.

Call in, write or telephone:

NORTH WEST OSTOMY SUPPLIES

North West House,
62 Oakhill Trading Estate, Worsley Road North, Walkden,
Manchester, M28 5PT. Tel: Farnworth (STD 0204) 709255
Proprietor: Maureen A. Nuttall. SRN RSCN QN

ADVERTISING

FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

Rates: £3 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 the next issue of LINK (August) should be in by the 6th July. Send to: The Editor, ASBAH, ASBAH House, 42 Park Road, Peterborough PE1 2UD.

HOLIDAY ACCOMMODATION

ED CROSS HOUSE, INVERNESS offers respite are/activity holidays throughout the year to disabled people over sixteen years of age. A 24 hour facility is provided by skilled care staff and voluntary helpers. Accommodation in hotel standard single bedrooms. For details of what we offer please contact: Mike Webster on Inverness (0463) 234939.

BOATING HOLIDAYS. Kingfisher I is a traditional steel narrowboat, but with a difference. This boat is from stem to stern designed and built for wheelchair users, you can actually handle this boat—without any problems—from a wheelchair. 60ft long, sleeping 6/7 people, with full central heating, TV and radio. Fitted with unique equipment including TWO hydraulic lifts, power steering, wide doors. Kingfisher I is based on the Shropshire Union Canal. If you are looking for that very special holiday this year contact Dartline Cruisers on 0829-260638 for a brochure.

SUNNY TENERIFE or scenic NORTH WALES?
For the past ten years families have been holidaying at our ecially adapted self-catering bungalow in Mold, Clwyd. Now addition to our luxury home (sleeps 4/5) we are venturing further afield—to the beautiful **'Mar y Sol Health and Fitness Resort' in Los Cristianos.** "Brilliant, Amazing", say the BBC's 'Travel Show' and believe me they are right! The complex is fully wheelchair accessible— even the swimming pools, saunas, gymnasium, bar and restaurant. Apartments/studios for holidays or OWNERSHIP. Sounds too good to be true? Don't believe it! If it's a holiday in MOLD or TENERIFE you want send now for your brochures to Lynne James, 7 Overpool Road, Ellesmere Port, LL66 1ZW. Tel: 051 339 5316.

SPECIAL OFFER FOR FAMILIES AT MAR Y SOL, LOS CRISTIANOS, TENERIFE. Children under 12 free accommodation and under 16 half-price, if sharing with parents, between 15 May – 15 September. Wheelchair accessible Apartments and Studios. Heated Pool, Restaurant, Video on request. For details of cheap flights and accommodation contact Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx. TW19 5NX. Tel: 0753 685718.

WESTWARD HO! NORTH DEVON. Holiday Chalet. Sleeps 6. Excellent Club, Swimming Pool, shop on site. Near sandy beach. S.A.E to Mr Oakley, 12 Farleigh Road, Perton, Wolverhampton. Tel: (0902) 751484.

WINTERTON ON SEA, GREAT YARMOUTH, NORFOLK. Chalet 6 berth. Pleasant site with all amenities. Pool, shop and bar with live music, play areas for the children, cycle hire, snack bar and take away food. Further details: Mr F Simmonds (0628) 783413.

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.

BLUE ANCHOR, WEST SOMERSET. Views of sea, Exmoor, steam-railway, close to beach. Privately situated terrace of 4 fully accessible bungalows equipped to high standard. Colour television, video, laundry, games room, linen and electricity included. For further details telephone Lorraine or Martyn Babb on Dunstar (0643) 821200.

FOR SALE

RENAULT 5 AUTOMATIC 1.4, 1984, (A. Reg.) Silver, full year MOT, fitted with push/pull hand controls, radio/cassette. Good condition. £1,500. Tel. Gill Johnson: 0235 464428 (Day), 086732 8149 (Evenings).

SWEDE 24 CHAMP WHEELCHAIR, Red/Grey, low back, fitted with sides and spoke guards. Good condition. £400 ono. Tel. Gill Johnson: 0235 464428 (Day), 086732 8149 (Evenings).

DIRECTORY OF LOCAL ASSOCIATIONS

BARNSLEY
Mrs Marlene Haigh,
3a Birk Avenue,
Kendray,
Barnsley, S. Yorks, S70 3AE

BEDFORD
Mrs Elsie Bennett,
341 Bedford Road,
Kempston, Beds. MK42 8PX

BOURNEMOUTH, CHRISTCHURCH & DISTICT
Mrs G. Lanning,
23 Seaway Avenue,
Christchurch, Dorset
Tel: Highcliffe 273 255

BRISTOL
Mr G Egan,
64 Rookery Road,
Knowle, Bristol 4
Tel: Bristol 777942

BROMLEY
Mrs M Nation,
13 Ash Road,
Green Street Green,
Orpington, Kent.

BUCKS & E.BERKS
Mrs G. Ayres,
19 Park Lane,
Hazlemere,
High Wycombe,
Bucks HP15 7HY

BURY & BOLTON
Mr David Clyne,
51 Cuckoo Lane,
Whitefield,
Manchester M25 5WQ
Tel: 061 798 7804 (after 4 pm)

CALDERDALE
Mr A L Crowther,
12 Elm View,
Huddersfield Road,
Halifax Tel: 0422 41497

CAMBRIDGESHIRE
Mrs D Thorn,
55 Hanbury,
Orton,
Goldhay,
Peterborough PE2 0QU
Tel: 0733 235139

CHESTER & DISTRICT
Mrs P Ithell,
34 King Edward Street,
Shotton, Deeside
Tel: Deeside 811074

DUDLEY & WOLVERHAMPTON
Mrs Lorna J Wootton,
14 Leveson Road,
Wednesfield, Wolverhampton,
West Midlands, WV11 2HF
Tel: Wolverhampton 738724

ESSEX
Mrs R McCarthy
26, Brixham Gardens
Ilford, Essex 1G3 9AX
Tel:081 594 1852

GLOUCESTERSHIRE
Mrs J A Wintle,
54 Borough Close,
Kings Stanley
Stonehouse, Glos GL10 3LJ
Tel: Stonehouse 2963

GRANTHAM
Miss Caroline MacCallum,
58 Redcross Street,
Grantham, Lincs. NG31 8BU
Tel: 0476 66085

GREENWICH
Mrs M. Mears,
29 Wellmeadow Road,
London SE13 65 Y
Tel: 081 698 5567.

HAMPSHIRE NORTH, W. SURREY & S.BERKS
Mrs Liz Selby,
The Old Police Station,
Woodbridge Road,
Guildford.
Tel: Guildford 571736

HAMPSHIRE SOUTH
Mr S R Baker,
12 Moorings Way,
Southsea, Portsmouth, Hants,
POY 8QW
Tel: 0705 819075

HERTS & S.BEDS
Mrs S. Riseborough,
4 Sherborne Way,
Croxley Green, Rickmansworth,
Herts. WD3 3PF.

HILLINGDON
Mrs B. Brannen,
30 Fairey Avenue,
Hayes, Middlesex

HUDDERSFIELD
Mrs J V Brook,
11 Standiforth Road, Dalton
Huddersfield
Tel: 0484 21776

HULL & DISTRICT
Mrs G D Brown,
233 Cranbrook Avenue,
Hull. HU6 7TX
Tel: Hull 857165

JERSEY, Channel Islands
Mrs Mollie Buesnel,
Villa Acacia,
Sunshine Avenue, Five Oaks,
St Saviour, Jersey, C.I.

KENT
Mrs S Dobson,
119 Punchcroft,
New Ash Green,
Kent DA3 8HS

LEEDS & BRADFORD
Mrs Jane Weston,
28 West Busk Lane,
Otley, LS21 3LW
Tel: 0943 465456

LINCOLN & MID LINCS
Mrs P Keyes,
Pinfold, Chapel Lane,
North Scarle, Lincoln
Tel: Spalford 781

LEICESTERSHIRE
Mrs A Twomlow,
29 The Crescent
Market Harborough
Leicestershire LE16 7JJ
Tel: 0858 32967

LINCOLNSHIRE SOUTH
Mrs P Mason,
67 Boston Road,
Heckington, Sleaford, Lincs

LONDON N.EAST
Mrs B A Pierson,
18 Kingsley Road,
Forest Gate,
London E7 9PP
Tel: 081 472 8605

LONDON N. WEST
Mrs H Prentice,
37 Milton Road,
Hanwell, London W7 ILQ

LONDON SOUTH
Mrs S Cudd,
15 Woodvale Walk,
Elder Road, W. Norwood,
London SE27 Tel: 081 761 2400

MANCHESTER CENTRAL
Mrs. Victoria Martin,
23, Mirfield Avenue,
Coppice,
Oldham OL8 1BW
Tel: 061 627 1819

MIDLAND
Mrs D Britt,
14 Court Road,
Sparkhill, Birmingham 11
Tel: 021 771 0371

NORTH EAST (Northumberland)
Mrs E Grant,
27 Redwell Road,
Prudhoe,
Northumberland

NORTHAMPTONSHIRE
Mrs J Cockings,
57 Little Street,Rushden,
Northants

OXFORDSHIRE
Mrs Shirley Dale,
14 South Row,
Chilton, Didcot,
Oxfordshire

PRESTON
Mrs S Thompson,
34 Beatty Road,
Southport, Merseyside,
PR8 6LB

ROTHERHAM & DONCASTER
Mr and Mrs D Barringer,
21 Coppice Gardens,
Broom Riddings, Greasbrough
Rotherham S61 4RE
Tel: Rotherham 560686

ST HELENS & DISTRICT
Mrs N Maddocks,
236 Rainhill,
Prescot, Merseyside L35 4LD
Tel: 051 426 3921

SALISBURY & DISTRICT
Mrs J Renshaw,
1 Philip Court,
Coronation Road,
Salisbury SP2 9DA

SHEFFIELD
Mrs C Crofts,
46 Busheywood Road,
Sheffield S17 3QB,
Tel: 0742 366033

SHROPSHIRE
Mrs A Ashfield,
35 Trenleigh Gardens, Trench,
Telford, TF2 6RN
Tel: Telford 612542

SOMERSET
Miss June Roberts,
18 Spicer Way,
Lords Leaze, Chard,
Somerset TA20 2JS
Tel: 04606 2333

SOUTHAMPTON & DISTRICT
Miss T. M. Joplin,
50, Westwood Road,
Southampton, SO2 1DP
Tel: 0703 585154

STAFFORDSHIRE
Mrs J Davies,
8 Oakhill Avenue, Oakhill,
Stoke-on-Trent ST4 5NJ
Tel: Stoke 45365

STAINES, HOUNSLOW & DISTRICT
Mrs G Paternoster,
12, Cordelia Road,
Stanwell,
Nr. Staines, Middx.
Tel: 0784 245606

STOCKPORT
Mrs S Silver,
1 Brookside Avenue,
Offerton, Stockport, Lancs.

SUFFOLK
Mrs Lynne Wall,
20, Townsend Road,
Tiptree, Colchester,
Essex CO5 0ND
Tel: 0621 817243

SUNDERLAND
Mrs Audrey Shepherd,
115 Holborn Road,
Sunderland
Tel: 091 528 3568

SURREY
Miss T A Bush,
6, Chipstead Lane,
Lower Kingswood, Tadworth,
Surrey KT20 6RG

SUSSEX
Mrs M White,
Averys,
Rusper, Horsham, Sussex
Tel: 029 384 217

TRAFFORD & SALFORD
Mrs T Gaynor,
Davis Court,
Cyprus Street,
Stretford, Manchester M32 8AX
Tel: 061 865 0222 mornings only

WARRINGTON & DISTRICT
Mr S. J. Charlton,
18,Saffron Close,
Padgate,
Warrington.
Tel: 0925 828767

WESSEX
Mr T Poole,
123 Gerrards Green,
Beaminster,
Dorset DT8 3EA
Tel: 0308 862614

WHITCHURCH & DISTRICT
Mrs D R Calder,
3a Bridgewater Road,
Whitchurch Shropshire

WIGAN, LEIGH & DISTRICT
Mrs Pat Stridgeeon,
24 Greendale Crescent,
Leigh, WN7 2LQ
Tel: Leigh 676091

WIRRAL
Mrs M Hudson,
28 Stavordale Road,
Moreton, Wirral, Cheshire
L46 9PR

WORCESTERSHIRE
Mrs Frances Bourne,
20 Grafson Place,
Droitwich. WR9 8NQ
Tel: 0905 772971

YORKSHIRE NORTH
Miss Faith Seward,
45 The Paddock,
York YO2 6AW
Tel: 0904 798653

WALES

Llanelli
Mrs Anita James,
61 Westland Close,
Loughor,
Swansea SA4 2JT.

Mid Wales
Mrs J Carter,
1 Meadow Road,
Craven Arms,
Shropshire SY7 9QY

North Wales
Mrs Barbara Meadow,
29 Sunningdale,
Abergele, Clwyd
LL22 7UB
Tel: 0492 824851

South Wales
Mrs Brenda Sharp,
38 Redbrink Crescent,
Barry Island,
S. Glamorgan,
Tel: Barry 735714

NORTHERN IRELAND

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

NON AFFILIATED ASSOCIATIONS

Blackpool & Fylde
Mrs Heather Pullin,
74, Newton Drive,
Blackpool FY3 8EP
Tel: 0253 36256

Beeston
Mr. S S Goodfellow,
6 Cyril Avenue,
Beeston, Notts.

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

Chesterfield
Mrs K M Tomlinson,
23 Hathern Close,
Brimington Common,
Chesterfield, Derbys

Cornwall
Mrs Wendy James,
17 Pergegon Parc,
Camborne, Cornwall
Tel: 0209 712191

Consett & District
M Broadley,
15 Girvan Close,
Burnside, E Stanley,
Stanley, Co Durham

Derby & District
Mrs A Hewitt,
St Merryn,
20 Burley Hill,
Allestree, Derby

East Anglia
Mrs L. A. Turner,
22 Windsor Drive,
Wisbech, Cambs
Tel: Wisbech 64483

Gainsborough & District
Mrs M Hawkes,
10 Turpin Close,
Gainsborough,
Lincs , DN21 1PA
Tel: 0427 616807

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

Lancaster, Morecambe & District
Mrs Dyson,
25 Royals Avenue,
Heysham,
Morecambe LA3 1PA

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

Teesside
Mr J Gray,
Marchesi Centre,
Tollesby Road,
Middlesbrough, Teesside
Tel: 0642 814458

OTHER ASSOCIATIONS

SCOTTISH SPINA BIFIDA ASSOCIATION

Executive Officer:
Mr Andrew Wynd,
190 Queensferry Road,
Edinburgh EH4 2BW
Tel: 031 332 0743

IRISH ASSOCIATION

The Secretary,
Irish ASBAH,
Old Nangor Road,
Clondalkin, Dublin 22
Tel: Dublin 01-572326

Any local secretaries who require changes please contact LINK Editor at:-

ASBAH HOUSE,
42, PARK ROAD,
PETERBOROUGH PE1 2UD
Tel: 0733 5555988