# Link

DECEMBER/JANUARY 1993 NO 143
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The magazine for people with
Spina Bifida and/or Hydrocephalus

## IN THIS ISSUE

HELEN MAKES A CHOICE FOR LIFE

A ROOM OF YOUR OWN

BACK IN THE USA!

ASSOCIATION FOR SPINA BIFIDA AND
HYDROCEPHALUS

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# Don't "Leave it to charity"

*Andrew Russell urges us to remind Social Services departments of their duties in providing services for disabled people.*

CHARITIES are having a hard time raising money at the moment. Like businesses and individuals, on whom we depend for our income, we have to be prudent in our actions, but ready with plans.

Nationally, ASBAH is on target in income and expenditure to break even this year, after a very difficult time last year. Next year, we expect to be able to expand our services a bit, if the recession does not turn into a slump. Local Associations are feeling the pinch too, but we are continuing to work together to provide advice, services and grants in very many areas.

However, apart from the recession, there is a further danger. The local authority Social Services give low priority status to their physical disability services. By and large they are passive, responding rather than initiating action to help disabled people.

Social Services look increasingly to the voluntary sector to provide basic necessities to their clients, as well as the 'luxuries' (which most of us may feel are also necessary). Equipment, adaptations, financial help, help with transport, with leisure pursuits etc - all are statutory duties where the need is established by assessment. But do they provide them? And what about the rumoured cutbacks in public expenditure?

At a meeting I recently attended with the new Chief Charity Commissioner, Richard Vries, he set out various aims. For example, he wanted to build a better sense of partnership with the charity sector; he wanted to monitor charities' finances and activities better. But he also referred to the "retreat of State-ism".

He made it clear that it was not for the Charity Commission to define the boundary between the State's duties and the work of charities, but it must be evident to him that, in the present government's policies towards health and social services, there is a strong strand of "leave it to charity".

This may or may not be an explicit aim, but it is certainly the outcome of the prevailing policies. Whilst there is nothing wrong with a tradition of charity service, many

Continued on page 4

*Cover: Your Voice, Your ASBAH - steering committee meets - see page 13*
*Photo courtesy of Peterborough Evening Telegraph*

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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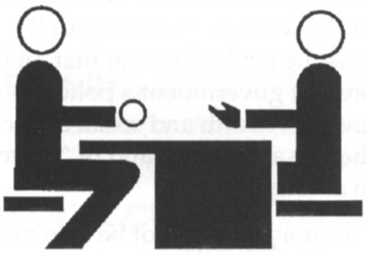
## Ulster on the air

An appeal on Radio Ulster, for Northern Ireland ASBAH, has raised £790 and donations were still coming in as LINK went to print.

Norman Nevin, professor of genetics, Queen's University, Belfast, asked radio listeners to support the NI Association in its aim to provide access to counselling for their members.



Margaret Reid, Chairman of the NI Association told LINK: "We are hoping to have the facility to refer individual cases to a counsellor when an urgent need arises for this service". Money raised from the appeal will be set aside for counselling fees.

## *Don't " Leave it to Charity"*

people believe that disabled people have rights to certain services. The trouble with leaving it to charity is that the rights of disabled people become compromised.

We have to be very conscious of this if we are not to collude, albeit inadvertently, with the trend. I am not suggesting that we - nationally or locally - should refuse to help people in need. But, as charities, we do have a duty to speak up about the needs we are meeting, and about those that remain unmet.

The best person to whom to direct these comments is usually the Director of Social Services, or the senior manager responsible for the local Community Care Plan. This plan - a requirement of the National Health Service and Community Care Act 1990 - is regularly revised and the Social Services department has a duty to consult voluntary organisations about their plan.

I believe that, whilst many local Associations have strong links with their Social Services department, many do not. Perhaps it is an opportune time for local Associations to invite a senior officer to their committee meeting, and to prepare for this by listing the issues that need clarifying or addressing locally.

The main duties of Social Services to people with disabilities are usefully summarised in a recent RADAR leaflet entitled "Are you receiving the support you need from Social Services?". The information in the leaflet will be published in our next Bulletin to all local associations.

With all the new policies and structures that have recently been introduced, and new procedures to finance them (such as the Poll Tax), I believe there is a real need at local level to remind Social Services departments of their duties, and to point out that our charitable services and grants are available in addition to, not instead of, their work.

## ASBAH seeks action on spina bifida clinic

ASBAH has complained that children wth spina bifida in Northern Ireland are being pushed to the back of the queue when it comes to receiving vital, corrective surgery at the province's paediatric orthopaedic clinic.

There has never been an official orthopaedic spina bifida clinic in Northern ireland. It was simply tacked on to a Tuesday afternoon fracture clinic at the Royal Belfast Hospital for Sick Children - where the number of fractures has risen by 65% since it was taken over five years ago by consultant orthopaedic surgeon Mr Kerr Graham.

This summer, the clinic had to cancel appointments for children with spina bifia because Mr Graham was overwhelmed by emergency fracture work.

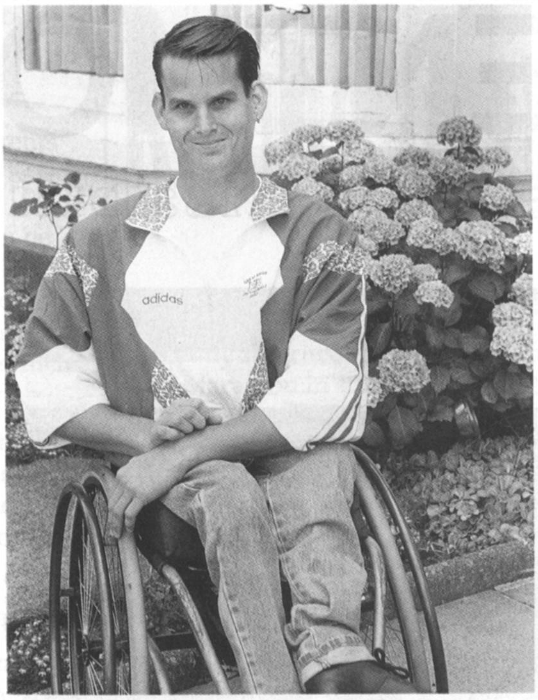
"The situation deeply worries our parents, and some complained to their MPs. One parent was even talking about going to the Ombudsman", said regional co-ordinator Meta Harvey.

Northern Ireland has one of the highest birth rates in the world of spina bifida - a situation we say which justifies the setting up of a fully-staffed, multi-disciplinary clinic for children with spina bifida.

"One problem with the present system is that, although children are once again being called in, this is at the last minute to fill gaps and they are not seeing all the specialists they need to on the same day", added Mrs Harvey.

As LINK went to Press, Mrs Harvey was waiting for an official response to a letter of complaint.

## The Golden Boy



A dream came true for Andrew Hodge, member of Preston ASBAH, when he returned from the para-Olympics with a gold medal.

Andrew, who has been wheelchair racing for 11 years, represented Britain in the 1988 Paralympics in Seoul when he finished fourth in the 100 metres. But this time he came first: "I was delighted to win the gold in the 100 metres," said Andrew, who is hoping to continue his globetrotting with a race in Florida, in February.

## Cricket victory

Over £700 was raised when ASBAH staff beat the Eagle Casuals from Lincoln at cricket on a rainy day in September. The match is held once a year in memory of top ASBAH fund-raiser Glyn Roberts, who died two years ago on his way home from Peterborough to Eagle, near Lincoln.

The loan of a Ford Escort estate, from main ford dealer T C Harrison, helped save on the expense of collecting raffle prizes and supplies for the game.

*TC Harrison car hire supervisor Fiona Wood hands over the keys of the weekend car to Andy Scrymgeour and Vicky Martin.*

## Changing places

Lynette Hare has joined ASBAH at our national office in Peterborough as secretary to the executive director. Mrs Hare, who previously worked for the city council, has taken over from Lyn Rylance who left in November to live in Tobago.

## Disabled workers' rights

At the end of November RADAR launched a campaign to inform disabled workers about their rights. They have published a comprehensive information pack: Employment Rights: A Guide for Disabled People".

*The pack costs £3.50 for individuals or £7.00 for organisations, incP&P. RADAR, 25 Mortimer Street, London W1N 8AB.*

## A step in the right direction

Britains's first "kneeling" buses are to go into service in North and West London next spring as part of a trial by London Transport. More routes in other parts of London will be given over to low-floor buses with 30 further vehicles still to be ordered.

"For the first time we will be able to offer a fast and effective means of getting wheelchair users onto regular mainstream bus services," said Andrew Braddock, head of LT's Unit for Disabled Passengers. "With the aid of a simple ramp, under the control of the driver, which extends out to pavement or road level from below the second door, wheelchair users can get on board with or without a helper."

## Hitting the headlines

**Into Europe**

Hot on the heels of her success in the UK Child of Achievement Awards (featured in LINK earlier this year) Ruth McClure from Northern Ireland has now been awarded a European Child of Achievement Award. Ruth was selected from 50 children from Europe and collected her award in Paris.

**In at the deep end**

And lifesaver Brain Waugh, who also featured in LINK after diving into a pool to help a struggling toddler, has saved a second life at Consett swimming baths. This time the trainee lifeguard, who is a wheelchair user, dived into the deep end to rescue a 10-year-old who was in distress.

# PARENTHOOD

## for people with disabilities

**The first national conference for parents with disabilities, organised by the Maternity Alliance, was held this autumn. Jane Williams and John Naude, from our Disabled Living Services team, were there.**

John Naudé is 'left holding the baby' at the conference

Many of the sentiments expressed in our 'Able Parents' feature (issue 130), in which we talked to mothers who have spina bifida, were reiterated at this conference. Speakers talked of the feelings of isolation disabled parents can face. Even though they may attend ante-natal classes (if they are physically accessible) they are unlikely to meet mothers-to-be with similar life experiences to their own. The attitudes and comments of others could also be hurtful:

"By becoming pregnant it says I'm a sexual being and some people have a problem with that", "People looked at me as a 'disabled girl', not a woman", "Her doctor should not have allowed her to get in that condition", "It's not fair for the child".

But there were also lots of positive messages for prospective parents: from those who felt that becoming a parent was the best thing that had happened to them; women who had really good support from their husbands; and those who found encouragement from the health professionals concerned with their care.

### Make contact with other disabled parents

Conference participants were given a chance to 'make contact' with those with common interests or experience. This is something which can also be done by any disabled parents, through **ParentAbility** - the National Childbirth Trust's network which supports pregnancy and parenthood for people with disabilities. They co-ordinate a national Parents Contact Register, for mutual support, and we know that they already have parents with spina bifida on the register.

### Maternity care guidelines

The conference issued detailed draft guidelines for good practice in maternity care. Briefly, these included:

*CHOICE - including the rights of disabled people to choose the type of care and place of birth

*EDUCATION - recognising that pregnancy is not necessarily high risk for disabled mothers

*INFORMATION - information for the parents and training in disability awareness for the professionals

*ACCESS - to services

*FINANCIAL SUPPORT - for mothers

*PRACTICAL AND SOCIAL SUPPORT - extra support for disabled parents at home such as equipment and transport.

*The Maternity Alliance has asked us to ask* ***you*** *for your comments on the Maternity Care Guidelines. A draft copy of the full guidelines can be obtained from DLS, ASBAH House, (mark your envelope MA guidelines) please return them, with your comments, for us to pass on to the MA.*

### How can ASBAH help

We are receiving increasing enquiries about parenthood from our disabled members as they approach this stage in their lives. In order to give appropriate information and advice, we would like to hear (from our disabled parents and those considering starting a family) what you feel would be useful. Write to John Naudé at ASBAH House.

John is currently compiling a parenthood and disability file - containing contacts, sources of information etc and would welcome questions or recommendations on this subject.

### USEFUL PUBLICATIONS

There are a number of useful publications for disabled parents and parents-to-be which are listed in the NCT's ParentAbility Resource List.The full list can be obtained from Jo O'Farrell, The Old Manse, 6 Forest Road, Crowthorne, Berks RG11 7EH. Here are just a few of those which readers might find of interest:

***Accessible Birth*** - a ParentAbility report on physical access to maternity units, by parents with disabilities.

***Support for Parents with Disabilities*** - an article from the NCT Postnatal Pack.

*Both the above are available from NCT headquarters, Alexandra House, Oldham Terrace, Acton, London W3 6NH. Tel: 081 992 8637.*

***The Emotions and Experiences of Some Mothers with Disabilities*** - an NCT booklet, price £2.90, from NCT Maternity Sales Ltd, Burnfield Avenue, Glasgow

**Where there's a will, there's usually a way: breastfeeding when the mother has a disability** - booklet from NMAA, PO Box 231, Nunawading, Victoria 3131, Australia.

***Equipment for Disabled People: Parents with disabilities, Sep 1989*** - general information on equipment which may be needed by parents caring for their babies. Available for reference through your Occupational Therapist. Published by Mary Marlborough Lodge, Nuffield Orthopaedic Centre, Headington, Oxford

***Pregnancy and the disabled woman*** - leaflet written by Jackie Rotheram, a disabled midwife. Free from Contact Television Ltd, PO Box 444, Bath. Tel: 0225 446688.

### HELPLINE

***ParentAbility (NCT) Practical Helpline*** - for parents with disabilities. Phone Kate Liffen 081 653 7430.

# Racing in the Big Apple

*John Naudé reports on the New York marathon*

I recently returned from the Big Apple, having completed the New York City Marathon in 4.5 hours, to raise money for Whizz Kids. The marathon itself was excellent, with lots of people at the side of the road supporting all the 'runners'. It was very similar to the London Marathon but a bit bigger.

The course went through the five districts of New York: Brooklyn, Queens, Bronx, Harlem and Manhattan. I made a decision that if I broke down in Brooklyn the Bronx or Harlem, not to stop, whatever the damage. These were mean looking neighbourhoods! At one point during the race I witnessed a fight at the side of the road - quick acceleration needed, I think!

The other interesting aspect of the race was my escort who was deployed to 'look after me'. It was quite amusing as it was his first marathon and it was I who found myself looking after him. At the end he looked awful, as if he was going to collapse, but he stood by me right until the very end.

New York is amazing, all those sky scrapers. The roads and pavements were not good, with hardly any dropped kerbs, but the public transport was excellent. Every bus I saw had an accessible sign displayed and the rail and underground systems were improving their accessibility. We travelled quite a lot using public transport and found it to be quite reasonable, with elevators (sorry, lifts) and one step to get on the rail system.

The attitude of the New Yorkers didn't seem to be particularly good but maybe it was just an aggressive attitude which you need to survive in the city.

Finally we went up the World Trade Centre but to get your ticket or to go to the information centre required a trip in the service lift for me, as they do not have a lift to the first floor. Lifts to all 107 floors except the first one!

Apart from this one inconvenience we had a brilliant time and it was wonderful to be able to use most of the public transport, maybe one day the UK will move in this direction. Until then - "Have a nice day!".

*John hopes to have raised around £3000 for Whizz Kids when sponsorship money is collected.*

# A Question of Image

*In LINK number 138 Mr Appleton and Dr Minchom of Wrexham Maelor Hospital gave a mid-term report on their research into Self Concept in Children and Young People with Spina Bifida. The project has now been completed and a presentation was given at Theatr Clwyd this autumn. This is a summary of their key findings.*

Young people with spina bifida feel less supported and less socially accepted by their peers than do able-bodied people. However, they feel well supported by their teachers.

Most young people with spina bifida compare themselves academically, socially and physically with able-bodied peers, rather than with other physically disabled peers. One consequence of this comparison is a subjective falling-short of expectation in these areas.

Of all the areas of self-concept measured in this study, it is the area of physical appearance that is most strongly associated with self-esteem. The association is stronger for young people with spina bifida when compared with able-bodied. Those who feel unhappy with their appearance tend to feel unhappy with themselves as people, and vice versa.

For a variety of reasons, adolescent girls with spina bifida are at greater risk of low self-worth than boys.

Both carers and young people wanted better transport and access facilities. Young people with spina bifida did not feel especially timid or uncertain about social situations - their main concern was gaining access and being accepted.

Continence, in spite of sophisticated assistance, remains a major problem - with only a minority achieving full continence of bowel and bladder. Though the majority appear to achieve independence in managing their bladder, few can deal with bowels unaided. Achieving continence and teaching the independence skills needed required considerable time and effort on the part of young people, their carers and their professional supporters.

The study confirms the wide range of disability in spina bifida with some young people achieving a near normal function, others being profoundly disabled.

It is evident that the level of self-worth and the achievement of independence is not simply related to the apparent physical severity of the condition. Young people with minimal physical disability may still be subject to profound difficulties and may be in as great a need for support as those more severely affected. More complex factors come into play and are the subject of further analysis.

The majority of the young people have had a high degree of medical intervention throughout their lives with many operations and prolonged periods of hospitalisation and illness.

Of the total sample, 3/4 were wheelchair users. In the Occupational Therapy assessment of a sub-sample of 39 children and young people in Clwyd, only half the wheelchair users had ramped or level access to the front door of their house. Accessibility via the back door was reported to be even less.

Whilst 92% of subjects in the sub-sample had a holiday last year, a very substantial proportion of these holidays were organised by Social Services and voluntary organisations.

67% of the sub-sample saw themselves as living away from home eventually. However, of these, the majority envisaged this would not happen until after the age of 21, and they would require special help to achieve it.

The vast majority of children and young people with spina bifida have carers who feel positive towards them. Out of 76 carers interviewed, 64 recorded very positive feelings and nine recorded mainly positive feelings. Positive feelings, if absent at birth, grow through caring for the child.

Carers view the child's disability as a family matter. They perceive themselves to be the main repository of knowledge about their child. They believe that family members offer the most emotional and practical support.

Whilst recording positive feelings towards their child and a personal growth through caring, carers express negative thoughts about the task of caring; the most common are the intrusion into personal and family freedom and the unending work involved.

Carers are very clear about service improvements they require on an emotional, practical and social level: a named worker who visits regularly to offer advice, support and counselling; information about spina bifida, benefits and resources; transport, access and adapted public facilities; aids and adaptations; an improved social life for themselves and their child. There is an expressed need for an improved educational and medical approach.

## RECOMMENDATIONS

1. There is a need to review how young people's wishes for more meaningful social integration with peers can be facilitated from infancy onwards, in school and in the local neighbourhood.

2. Traditional, functional interventions such as surgery, mobility work and continence work, need to be reviewed in light of the fact that these interventions involve the child's body and her feelings about her body. Developmental considerations based on the very close association between self-esteem and feelings about the body match sections of the Children Act which places great significance on the child's sense of control, right to choose, and centrality in planning, with her family, what specific types of help are required.

3. Careful consideration to be given to the need for children to have regular and consistent access to an adult to whom the child feels able to disclose personal worries, concerns and wishes. This might be a family member or an agency worker and the role must be distinguished from that of care/case manager, although of course the roles are not mutually exclusive.

4. Pre-school work to be reviewed in light of the fact that self-concept, and a basic sense of personal worth, develop in the second year of life, in tandem with consolidation of attachment, peer social exploration and the growth of autonomy. There is a need for research in this area to go beyond functional interventions and physical outcome measures, to include more balanced developmental approaches.

5. An integrated approach that respects and utilises family knowledge and expertise and, in turn, offers a clear appraisal of its own expertise and resources would match the aspirations both of the families and recent legislation.

6. Of all the practical needs that emerged, the most important seems to be the need for improved access to public places, improved facilities within public places and an improved transport system.

Acknowledgements:

The core team and the research assistants would like to warmly thank the children and carers who took part in the research; Dr Martin Bax and ASBAH for their funding and much appreciated support; all professional colleagues in every field for their valued and valuable co-operation.

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### *The Study*

*A geographically defined sample of 79 young people with spina bifida, aged seven to 18, were given a psychosocial, medical and occupational therapy interview. Carers also received a structured interview. 79 matched able-bodied young people received the psychosocial interview.*

### *Core Research Team*

*Peter Appleton and Dr Philip Minchom (Department of Paediatrics, Ysbyty Maelor, Wrexham); Vicki Boll and Pat Jones (Dlwyd Social Services Department); Dr Nick Ellis (University of Wales at Bangor).*

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## Benefits guide

A Benefits Guide for Young People and Children with Disabilities is now available.

The guide provides helpful information, giving the range of benefits available both to disabled children and adults and to their carers. There is also a section on other sources of help. The booklet includes a list of useful free telephone numbers for DSS Advice Lines in many languages.

The booklet is produced by the Disability Alliance at a cost of £4.00 (£3.50 if on Income Support), post free. It is available in English and Bengali andcan be obtained by writing to:

*Disability Alliance, Universal House, 88-94 Wentworth Street, London E1 7SA.*

## Why are we waiting?

If you are wondering what has happened to your claim for Disability Living Allowance, you are not alone. DLA was introduced in April and some people have had to wait months to have their claim processed. In September 148,000 claims for DLA were outstanding.

Chief executive of the Benefits Agency, Mr Bichard, has said that efforts are being made to redeploy staff from other areas of the DSS to clear the backlog.

# A room of your own

TWO years after the first tenants arrived, the small North West London ASBAH housing project at Rosemont Road in Acton, west London, looks almost as neat and tidy as the day it opened.

There is little to tell the properties apart in this leafy corner of the city - tucked away out of sight and sound of the nearby arterial road carrying traffic from central London to Heathrow and beyond.

Prosperous 'fifties semis peek out between trees. The occasional later block of flats blend into the background.

Outside No 62 Rosemont Road, an electric-powered buggy is plugged in for a recharge. Inside, only Sigourney Weaver from 'Aliens' would be worried by small holes in the corner of the living room carpet, etched out by acid from a leaking wheelchair battery.

*North West London's house in Rosemont Road, Acton*

This substantial semi - with fruit trees out the back and a raised-bedded front garden - has been converted into accommodation for four young people with spina bifida and/or hydrocephalus by Ealing Family Housing Association. It is managed by the local ASBAH.

Together, they have done a lovely job. There is parquet flooring, good furniture, a fully-adapted kitchen, a list of simple house rules of the 'be considerate to each other' variety by the phone, a lift to the four bedrooms on the first floor and a part-time project worker to provide support.

Shops, including a Safeway store, are a short distance away. A nearby adult education college is accessible and has a full range of courses. Tenants are strongly encouraged to follow interests outside the house.

There is a vacancy and applications are invited. The original idea had been to fill the house with people from Ealing and North West London, but this did not work out. So they will now consider applications from around the country.

"Being part-time, the project worker can only offer minimum support and this cannot be daily", said project treasurer and acting chairman Eric Prentice.

"The worker is there to provide advice and assistance in such areas as budgeting, benefits and form-filling, education and employment but has been known to help in compiling shopping lists and taking them to local stores until they know their way around."

Tenants are expected to manage their own personal care completely, and to be able to perform basic domestic tasks. Getting other people to do one's ironing and cooking does not go down well.

The committee need to interview the prospective tenant more than once and to check their ability. "Those coming our of Five Oaks come with a reliable assessment, but some other establishments' assessments need to be questioned in a 'left alone to do it themselves' setting", said Mr Prentice.

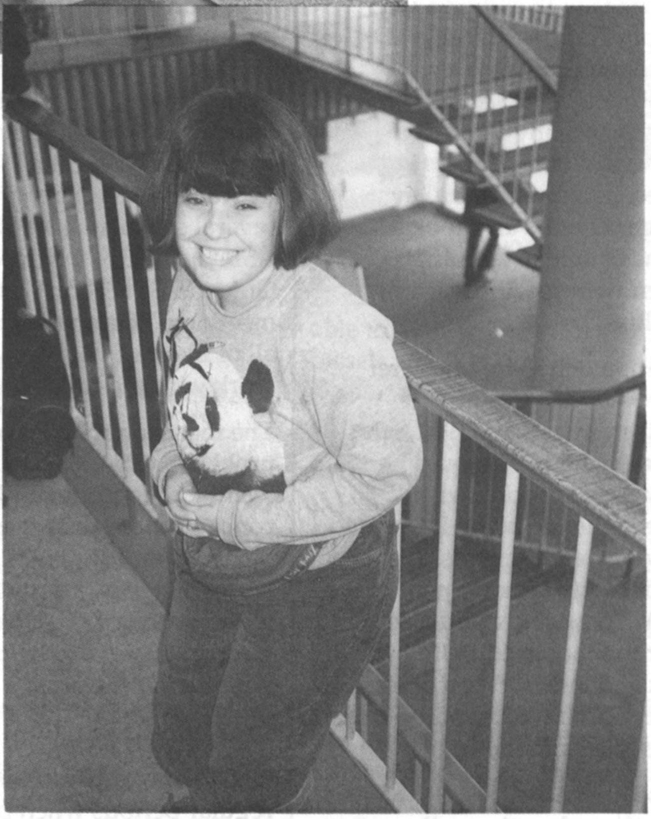
"The tenant needs to be able to deal with money, as spending all their benefit on trivia and books will mean going fairly hungry soon after. The project worker cannot be there each morning to hand out pocket money like a parent".

As in any big city, a bit of resilience will be required by newcomers until they settle in. "We do not think the community spirit and support is the same in a

London suburb as that in a small town or rural area", added Mr Prentice.

***Inquiries about Rosemont Road: Mrs Hazel Prentice, 37 Milton Road, London W7 1LQ, or your fieldworker.***

*Kirk Watson (30) came to Rosemont Road after an independence-training course at Five Oaks. He has settled in well and started a photography course at the local college.*



*Lisa Castle (24), another tenant at Rosemont Road, seen at Acton College where she is taking a computer course.*

SUSSEX ASBAH is looking for tenants for their nine-bedroomed house 200 yards from the seafront at 5 Grand Avenue, Worthing. The house aims to be a stepping stone on the way towards greater independence.

Assistance with personal care is not given by staff but, at present, community nursing and home care support is available. A member of staff sleeps in to be able to respond to any emergencies at night.

Prospective tenants are invited, first, for an informal visit. If still interested, a two or three-week stay for a trial period is arranged. If this is successful, the successful applicant can move in when a vacancy arises (at present there are several vacancies).

***Worthing inquiries: Mary Hill 0273-220776 or Val Hardy 0444-453630.***

MIDLAND ASBAH this year opened Artingstall House, 10 flats at Stirchley, a Birmingham suburb about five miles south of the city centre. There are no vacant tenancies at present but inquiries are welcomed - with priority given to people living in the Midland ASBAH area of Birmingham, Solihull, Sandwell and Warwickshire.

Six flats on the ground floor are built to wheelchair-standard, while the remaining four on the first floor are designed for people with few mobility problems or with hydrocephalus. All the flats are linked to a 24-hour emergency call system.

A project enabler lives on the premises and provides support to residents for 35 hours a week.

The property - developed by Sanctuary Housing Association - was named after the late Mrs Dorothy Artingstall, chairman of Midland ASBAH for 16 years.

***Artingstall House inquiries: Mrs D Britt, 021-771 0371.***

# Down Your Way

*Several local associations lend financial support to the provision of a fieldworker in their area . In Sussex they also have their own part-time education adviser - here Mary Rudling tells us about her work for SASBAH.*

"I have been working for the Sussex Association for Spina Bifida and Hydrocephalus for 18 months as their education adviser. I work four hours a week. My job involves giving support to schools and parents with children who have spina bifida and/or hydrocephalus. Before my appointment with SASBAH I had taught at Anthony House - a further education college for disabled students, at Chailey Heritage school. I also took a diploma course in teaching children with specific learning difficulties.

I was approached by Margaret White, SASBAH County Organiser, in January 1991, who asked me whether I would be interested in working with children who are being integrated into mainstream schools. We advertised my appointment in the SASBAH newsletter and also sent a letter to schools, initially in East Sussex and later in West Sussex. I had a considerable response from schools and parents.

To-date I have visited 30 schools, one further education college, two playgroups and I have made a number of home visits. Most of the children I have seen have been in primary schools but gradually they are moving up into secondary school and an important aspect of my work is to act as a link to help smooth the passage from junior to secondary school.

I work in close liaison with ASBAH disabled living adviser Leonie Holgate, who has been working for a number of years in schools in Sussex and other areas, giving advice and support to teachers and parents. Leonie has been very helpful and is always willing to share her considerable expertise.

When I visit a school I generally speak with the headteacher, class teacher and ancillary helper and then spend some time observing the child in class. Obviously, the type of support I give varies in each school, some just need reassurance that they are doing the right things while others are pleased to receive information and suggestions on how to help with the quite specific learning difficulties which many children with spina bifida and hydrocephalus experience. In several schools I have shown the ASBAH video - 'Hydrocephalus a Guide to Education' - at staff meetings. This enables me to reach all of the staff who are likely to work with the child.

The most common learning problems which I encounter when visiting schools are: lack of concentration, poor manual dexterity and slowness in performing tasks and difficulty with numeracy. There are a number of ways to help children with these problems:

**Lack of concentration**

One to one teaching (for short, regular periods when practical), controlling the length of a task, using tapes and headphones, considering seating position in class.

**Poor manual dexterity**

Combine continued handwriting practice with developing keyboard skills, preparation of simplified worksheets to reduce 'copying out'.

**Numeracy**

Use of concrete objects - making use of touch and sight, verbalise to help internalise concepts, focus on 'practical maths'.

Other learning difficulties experienced by some of the children I visit include poor comprehension (although word recognition is often good), difficulty in following instructions, not knowing how to start on a task without help, and lack of organisation.

Of course, there is a wide range of ability amongst children with spina bifida and hydrocephalus, some of the children I see don't experience any learning difficulties whilst others have quite severe problems. I do find that children with hydrocephalus experience some different problems at school from those with spina bifida. It can be more difficult for a child with hydrocephalus to be Statemented as the disability may be 'unseen'. Hydrocephalic children may not need physical support in schools but they often need extra help with their learning. On the other hand, children with spina bifida generally have a statement and ancillary help, however there is a danger that they will become over-dependent on their ancillary helper and it is important to discuss ways in which ancillary helpers can give support while encouraging independence.

I am often asked questions on other aspects of school life, notably how to include children in PE lessons. Swimming and weightlifting are very useful skills for children with spina bifida to develop, however it is important for them to participate in PE and games as fully as possible and there are some schemes such as the '10 step award' which enable disabled children to follow similar activities to their peers.

A number of 'needs' have become apparent as I visit schools. Firstly there is a lack of knowledge and information available to schools when a disabled child is being integrated. Organisations such as SASBAH can play an important role here. We have run a Day School, in conjunction with Chailey Heritage, for ancillary assistants and as I write we are organising a similar day for teachers in the Autumn. However, I feel that Day Schools are a short term measure, ideally information on individual disabilities needs to be incorporated into initial teacher training programmes.

Also, I feel that schools are often isolated - it would be helpful to establish a link between mainstream schools where children with spina bifida and hydrocephalus are being integrated. It is also important to set up contacts between primary and secondary schools as children move through the education system. Considerable experience and expertise is developed by staff in primary schools which can usefully be shared with the child's next school.

Finally, there is a very important 'need' to praise schools for the work they are doing. In all of the schools I have visited I have seen a very positive and enthusiastic attitude towards integration. Staff are giving children time and support without 'singling them out'. A lot of team work is required to ensure successful integration - teachers, ancillary assistants, and parents all need to work together. Certainly local organisations such as SASBAH can also play a very important role in supporting and developing integration."

### Your Voice, Your ASBAH

## Steering committee meets

*Terry Denyer reports on the first meeting of the steering group set up to help ASBAH's disabled members have a more active role in the Association.*

"Following the well-attended initial meeting held at Peterborough in May, those people who expressed interest in forming a steering group to carry forward the ideas discussed at "Your Voice, Your ASBAH", held a meeting on 21 October.

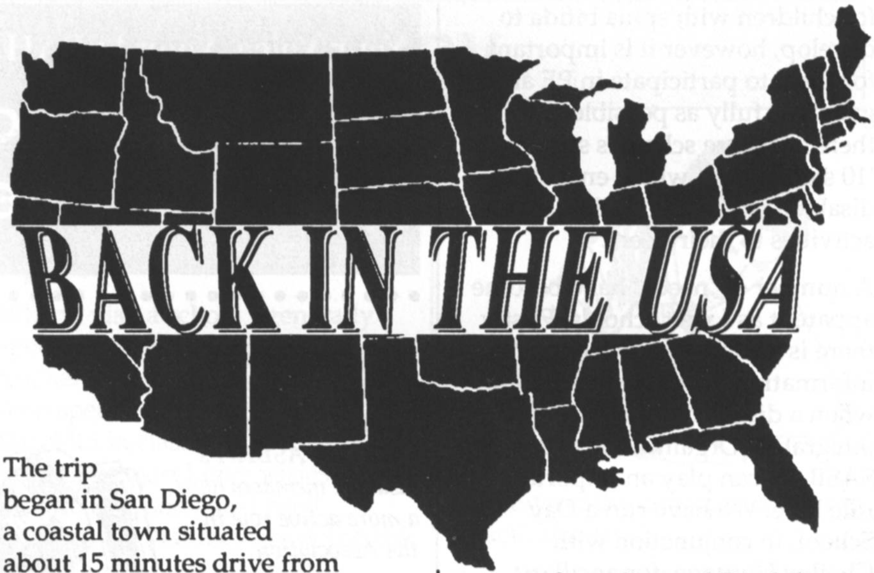
Regrettably only three members were able to attend: Kevin Towner, Jonathon Burke and myself. Andrew Russell and Tony Britton were in attendance for much of the day.

After Andrew's very clear explanation that the group would receive his and all ASBAH staff's support and encouragement, in all it wanted to do, there had to be no doubt that there could be no new money to finance extra initiatives. Any major expenditure would at least have to be found from other votes or alternatively mean deciding between one activity or another. We were advised as to the full range of ASBAH's services and the fact that about 15,000 members were more or less constantly being assisted in one way or another by ASBAH.

We questioned why ASBAH never seemed to be quoted in the national media - be it newspapers, TV or radio - in the way that the Spastics Society, NSPCC etc are on any particular social issue. Andrew explained that even after 26 years ASBAH is, in comparison to these other groups, so small that even a letter to The Times from him would almost certainly not be printed. There followed much other discussion about ASBAH's public profile as there was about forging links with other groups for and on behalf of other disabled people. How best to get as many people with spina bifida and/or hydrocephalus together for a social/information and ideas swapping session and how long it should be for - one day, a weekend, or more? And would a LIFT-type event be appropriate or is something very different now required.

Through all the above and discussion on such things as Telethon and Children in Need appeals, there was both agreement and disagreement. The one thing on which we were *all* agreed was, at its next proposed meeting on 9 January 1993, it was hoped that many more members of the steering group would be present so that decisions would be made to carry us further forward. It was also agreed to send a questionnaire to all those people who attended the initial meeting in May."

# BACK IN THE USA



***Maddie Blackburn, ASBAH research fellow, writes about her teaching fellowship arranged by the Association of Spina Bifida of California and the University Children's Hospital of Los Angeles, USA.***

"At the 36th annual conference of the International Society for Research into Spina Bifida and Hydrocephalus, Dr Martin Bax and I presented some of the survey results from two ASBAH research projects: 'Transition into Adult LIfe' and 'Sexuality and Disability in Spina Bifida'. It was at this meeting that Dr Robert Jacobs, medical director of the Spina Bifida Association of California, invited me to present some of our research at their charity's conference in Orange County, as well as to teach at the Children's University Medical Hospital, Los Angeles. To represent my profession and ASBAH in the USA was too good an opportunity to decline.

*The family I left at home*

The timing was perfect - it coincided with the 46th Scientific Meeting of the American Academy of Cerebral Palsy and Child Development (AACPDM) in San Diego, where Dr Bax and I were already scheduled to run an instructional course.

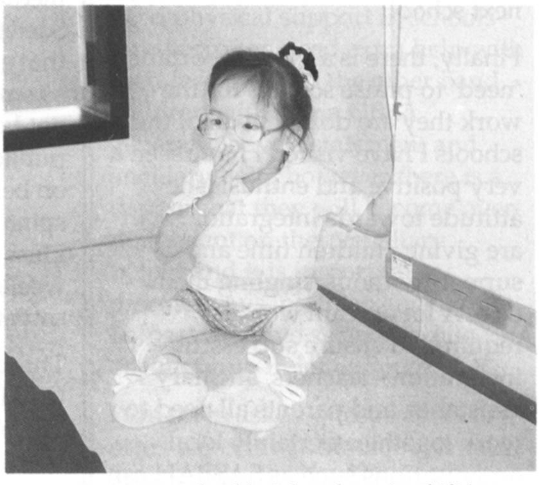
Organising domestic and school rotas in advance of my departure was almost as complicated as preparing the materials for the various programmes on my itinerary. I took comfort from Mary White's wisdom (see October LINK), filled the freezer, packed my case, left loving words and messages scattered round the house and set off for California.

The trip began in San Diego, a coastal town situated about 15 minutes drive from Tijuana, Mexico, and about 60 miles from the sprawling district of Los Angeles in Western California. Undoubtedly a befitting venue for the 46th meeting of the AACPDM. This multi-disciplinary meeting attracts in excess of 600 delegates, mainly from the American continent plus a handful of Europeans.

The meeting offered a comprehensive programme on the subjects of cerebral palsy, spina bifida, and developmental disorders. Both the medical and social management issues of these disabilities and disorders were discussed. For those requiring a little light relief to recover from scientific overload, or just plain jet lag, a visit 'downtown' or a coastal drive provided pleasant off-duty relaxation, providing you could fit it in before 8am or after 8pm!

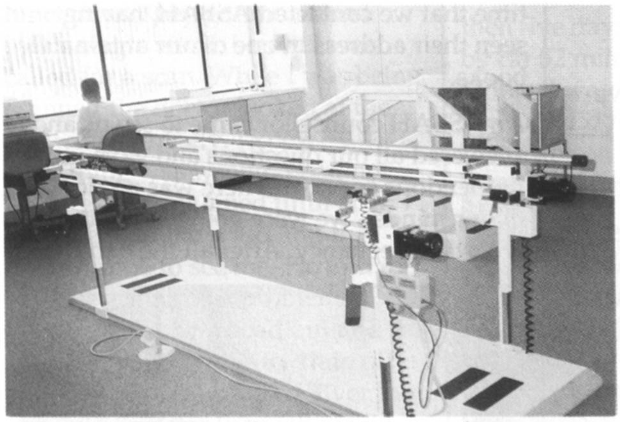
Dr Bax and I gave our instructional course on Sexuality and Disability on the final morning of the meeting. That afternoon, I was hastily chauffeured to address the Western Regional Conference of the Spina Bifida Association of California. The theme of this meeting was 'Spina Bifida: Prescription for Progress".

I was also scheduled to teach on the other days of this meeting. My programme here included Independence, Adolescent Health Clinics, Adolescence, Self Esteem and Sexuality. The conference was aimed at primary consumers and families as well as health care specialists. Many of the sessions were combined, others specifically addressed either professional or family/client groups. I taught both groups.



*An 18-month-old girl at the spina bifida clinic in Los Angeles*

The family groups invited me to join some of their "Rap"/Informal Discussion Sessions. Among other subjects, they discussed Independence, Continence Management, Sexuality and Career Aspirations. Internationally, issues, concerns and considerations about their disabled son or daughter's future seem to be similar. Will they be able to live independently, find and hold down a job, make friends, pay the bills etc. There were concerns about employment and the difficulty of trying to join an already depleted job market. I sensed that some of the more sensitive issues such as sexuality are more easily confronted and discussed in England, even if our own country fails to provide adequate answers to some questions. I was impressed by the knowledge and interest expressed by many families, particularly about continence management and some of the new techniques, notably: Antegrade Continence Procedure, ACE procedure, continent conduit operations.



*Physio equipment at Los Angeles Children's University Hospital*

Sadly, the recession has also affected the USA and there were only about 100, instead of the anticipated 300, people at this meeting. Because of this, the programme was condensed into two and a half days rather than three and a half. However, despite the reduced numbers, some of the individual group sessions were combined and provided lively, interactive and often controversial debate.

My next stop was Los Angeles, where I felt very privileged to be a house guest in the Jacobs family home in Beverly Hills. After a whistle stop tour of the Children's University Hospital, I joined Dr Michelle Roland, adolescent physician, in her out patient clinic for young adults with spina bifida. The format of their clinic is very similar to that of our adolescent (NTD) clinic run by Dr Richard Morgan at Westminster Hospital. She co-ordinates adolescent services, usually seeing patients at six monthly intervals, referring as and when necessary to orthopaedic, urology and neuro surgeons. She works collaboratively with a variety of health care specialists, including psychologists, social workers, physiotherapists, clinical nurse specialists and technicians etc. The majority of patients attending her clinic only conversed in Spanish. Dr Roland is bilingual. My own somewhat rusty A Level Spanish was also put to the test! Fifty per cent of the Los Angeles population are Hispanic, many of whom only speak Spanish. The majority of the patients seen by Dr Roland had no health insurance. Yet, despite this, all patients are given a comprehensive examination and any necessary investigations and tests are arranged. (This is not routine in all hospitals). She interviewed the young adults independently of their parents and discussed a whole range of issues as appropriate - schooling, independence, sexuality and, in one case, retrospective disclosure of sexual abuse. Child protection policy guidelines are similar to those followed in the UK.

My next visit was to address a multi-disciplinary group of health care specialists working in the Spina Bifida Centre of the University Children's Hospital of Los Angeles. Other teaching sessions included a 'Grand Round" lecture to paediatricians, geneticists, medical students and other multi-disciplinary health specialists.

in addition to lectures, I attended the paediatric Spina Bifida outpatient clinic in Los Angeles Children's Hospital, participated in a newly formed Self Advocacy, Disability Rights group in Glendale and attended a meeting discussing ethnical, religion and disability issues in Los Angeles. I also visited an American primary school and observed children "clocking in" for registration and declaring their daily oath of allegiance to America!

In the USA, topical discussion issues concerning spina bifida include the use of pre-conceptual folate supplementation, general allergic reactions , new surgical procedures for preservation of renal function, urodynamics and continence, outpatients and home record keeping using computers, and psycho-social issues in relation to adolescence.

The Americans idealise the traditional ethos of the British National Health Service and are sad to see our country appearing to dismantle a system which to them was once regarded as exemplary throughout the world. The Americans hope Bill Clinton will develop a similar system based on the British NHS philosophy; as one American doctor described it to me:

"the right, choice and access of health and treatment for everyone, irrespective of culture, gender and most of all, financial status".

# Helen's Choice

**Amniocentesis revealed that Helen Vaughn's baby would be born with spina bifida. Helen was given a week to decide whether to go ahead with the pregnancy.**

*The subject of whether to continue with a pregnancy when the mother-to-be knows the child will be born with a disability was discussed on 'A Choice of Life' on Channel 4 earlier this month. Helen took part in that programme, here she retells her story for LINK readers.*

"After 18 months of trying to get pregnant, and after our GP decided to refer us to the fertility clinic for tests, we discovered that I was going to have a baby. We were both over the moon.

*I see my daughter for the first time*

Time progressed and we went to the ante-natal booking-in clinic. This was fine, apart from a two-hour wait. The midwife discussed the pregnancy with us and asked if I would like the AFP blood test to screen for abnormalities which included spina bifida. I agreed and had some blood taken. Four days later I received a phone call at 8.30 am, it was the hospital. They told me that there may be a problem and I was to go for another AFP test. I arrived at the hospital an hour later. All in all I had three AFP tests and they were all raised.

By this time I was 16 weeks pregnant. I was called into the scanning room to see if anything could be detected by ultrasound. Unfortunately the baby was in a difficult position and the consultant couldn't see the spine well enough. Another appointment was made for two days later, for a re-scan.

Although the consultant still couldn't see the spine properly he had a suspicion that all was not well. He then proceeded to perform an amniocentesis. This was not a very pleasant experience.

A week later we were given the news that our baby had spina bifida.

The consultant gave us a week to decide on whether to carry on or terminate the pregnancy. We left the hospital with very heavy hearts and did not know where or who to turn to. We did not know what spina bifida was as very little had been explained by the hospital. It was at this time that we contacted ASBAH, having seen their address in one of our ante-natal books.

*Seven weeks old - waiting for a new shunt*

An ASBAH counsellor came to see us and answered all our questions and gave us tremendous support. There was no doubt in our minds - we were going to continue with the pregnancy. After all the baby would be given just as much love, if not more, than if there was nothing wrong and we could give her the best possible chance in life.

A week later we arrived at the consultant's office where we told him of our decision. He said that we were a very brave couple and if it had happened to him he couldn't go through with it.

Our ASBAH fieldworker suggested that we speak to the paediatrician, who would be looking after the baby, so that he could answer any questions we might have. He told us exactly what was going to be done in the baby's first few weeks of life. We both felt a lot better when we knew what to expect after the birth.

As the weeks progressed I had regular check-ups. Because the baby was not kicking I had to be scanned every three weeks and, as the time got nearer, I was scanned every week. The consultant told us that the baby's head had begun to get bigger and he was going to have to keep a very close eye on it.

When I was 37 weeks pregnant, I was booked in for a caesarean as the baby's head had become very large. The caesarean was to be performed on Wednesday 2 October, 1991. I was to report to the ward the day before, at lunchtime. They got me settled into a single ward, before I was called for a scan. While I was being scanned the doctor looked at the midwife strangely. I knew something was wrong. I had not been really frightened until now. I went back to the ward and the doctor came to see me. He told me that there might be problems getting the baby's head out and that they might have to drain off fluid before they could deliver the baby. The doctor then left me, in tears, not knowing if the baby I wanted so much was going to live.

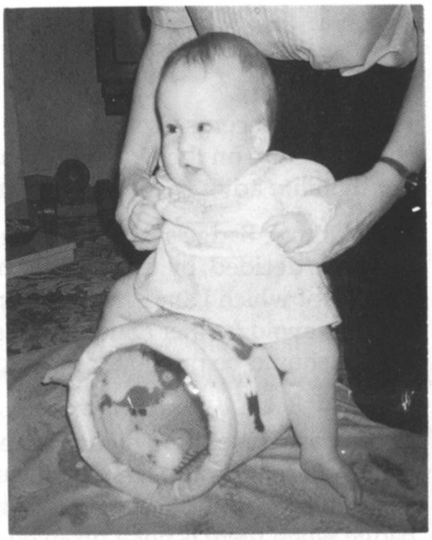
I asked to see the paediatrician again, to explain things in more detail. He told me it would be all right and he did not think they would have to resort to draining fluid.

Mick came to see me at visiting time and when he left I just panicked, so the sister came to see me. She took me into the Special Care Baby Unit, to see where my baby would spend the first few hours of life. I eventually got to sleep that night and woke at 6.00am to get ready for theatre. I was due to go at 8.30am but they were running late. By 10.45am I was on my way to theatre.

I wanted to stay awake during the caesarean but they could not get the spinal block to work, so in the end I gave in and had a general anaesthetic. At 11.45am I gave birth to a baby girl - Hollie Christine - she weighed 8lb 2.5ozs. I didn't see Hollie even though I was awake quite quickly. She was transferred to the Alder Hey Children's Hospital, Liverpool, when she was just two hours old.

On Friday 4 October, Hollie's back was closed. The doctors were concerned that it might break down as it was a very tight closure.

I had a 10-inch cut due to the caesarean but I made myself get out of bed the next day because I wanted to see my daughter so much. I was allowed to leave hospital on 6 October, Hollie was then five days old. I then travelled by car 52 miles to Liverpool to see Hollie. I wasn't allowed to pick her up but I did feed her in her incubator.



*A physio session at home*

Three days later, Hollie had her first shunt inserted. Then, on Tuesday 15 October, Hollie was dressed for the first time and her incubator was switched off. We were told that if everything was okay she could go into a plastic cot the next day. A few days followed and Hollie made excellent progress - we were told we could take her home on 20 October. She was now all ours, at long last.

Everything was going well but when we took her to outpatients clinic her veins on her forehead were protruding. The doctor told us to take Hollie to Alder Hey Neonatal unit. Doctors confirmed that Hollie's shunt had blocked and on 15 November she had a new shunt fitted. The next day doctors told us that the new shunt had also blocked and she had an infection. Hollie became very poorly.

They decided to exteriorise the valve from the stomach to see if that would help. After three days of this they took her back to theatre and removed the shunt completely. Hollie then had a valve which was on the top of her head and this drained fluid into a bag outside her body. This method was used until all the infection had cleared.

Hollie returned to theatre once more to have a new shunt fitted on the other side of her head. This meant she didn't have any hair apart form a little tuft at the back of her head.

During Hollie's stay in hospital it was confirmed that she was allergic to dairy products and she was changed on to soya milk.

Months passed and, apart from a light cold, everything had been fine. Then, on 5 July this year, I noticed that Hollie's shunt was very large and squashy. Hollie was admitted yet again with another shunt blockage. The doctors decided to keep the shunt in and insert another one on the other side of her head - this did the trick. So she now has two shunts - one on each side. This time she was in and out in four days. The nurses were amazed at how quickly she got over her operation.

On 2 October 1992, Hollie had her first birthday and she had a big party. We now take her to hydrotherapy and physiotherapy each week and she keeps us very busy. Hollie is a very happy and extremely content little girl, who gives us hours of enjoyment. And with all the help and love she has from relatives and friends, we hope she will become a very determined little girl.

All we ask of her is that she keeps smiling. "

# Eureka!

If you have an idea, a creative invention or have designed a simple new appliance which could assist someone with a disability in their daily living, Disability Scotland want to hear from you. At their Mobility Roadshow there will be a 'Tomorrow's World' corner where the inventions or appliances can be exhibited and could attract the attention of any prospective investors.

The Scottish Mobility Roadshow will be publicised widely throughout Britain and will be held from 20-22 May 1994 in Edinburgh.

*Karine Neill, Co-ordinator Scottish Mobility Roadshow, Disability Scotland, Princes House, 5 Shandwick Place, Edinburgh EH2 4RG.*
*Telephone: 031 229 8632.*

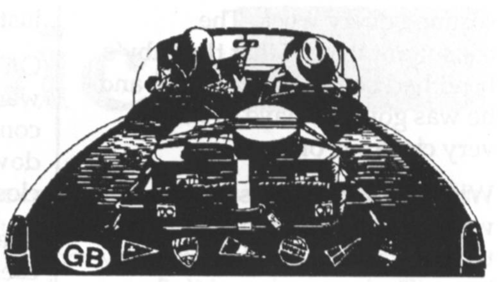
## Holiday brochure available

The Winged Fellowship Trust's holiday brochure for 1993 is available now.

The Trust provides holidays for physically disabled people in five purpose-built centres around the country. A children's week is being held from 24-31 July 1994 at a cost of £100. They also hold a variety of special interest breaks during the year: fishing, drama, music, art, crafts, outdoors etc. Contact them for more details or a copy of the brochure:

*Winged Fellowship, Angel House, 20-32 Pentonville Road, London N1 9XD.*

# Worldwide travel



A country cottage in France, on safari in East Africa, diving in the Caribbean, or touring America - whatever adventure abroad you might be planning for 1993, a new worldwide travel guide for disabled people aims to provide information to help you plan a successful trip.

General information and advice on transport, insurance, contacts, specialised services and accommodation listings are included in the guide: - the seventh edition of Holidays & Travel Abroad 1993: A Guide for Disabled People, edited by John Stanford. Price £3.50 (inc P&P). Published by RADAR.

*RADAR, 25 Mortimer Street, London W1N 8AB. Telephone: 071 637 5400*

## Parking incognito

Following concerns expressed by a parent in our last issue, that her child's picture on the Orange Badge would be 'on display' to passers by, our mobility adviser, John Naudé wishes to allay any fears:

"The Orange Badge system has been abused over the years.It was therefore decided, by the Joint Committee on Mobility for Disabled People (of which I am a member) and the Department of Transport, that to try to avoid further abuse of the scheme, a photo of the disabled person should be put on the *inside* of the badge, and then *covered* by two flaps.

This means the photo will not be seen by passers by but it does mean that, if there does appear to be misuse, a traffic warden can challenge the driver to show the photograph. This should prevent people using the badge when there is not a disabled person *with them* in the car.

## Working for better rail services

Platform is the name given to an alliance of voluntary sector and rail-user groups which is calling on the government to improve the railways. ASBAH is amongst the supporters of Platform, which was launched in October.

Amongst the issues Platform wants to see addressed by the railway privatisation bill is accessibility. "Access to stations should be safeguarded and improved and operators of trains and stations must have a duty to access and accommodate the needs of passengers with mobility difficulties," says Platform and it should be the statutory duty of operators to consult with user groups to maximise accessibility to all facilities.

A newsletter, Platform Bulletin, will give regular updates on privatisation plans. To receive Bulletin or for further information about Platform, contact:

*Platform, c/o Transport 2000, Walkden House, 10 Melton Street, London NW1 2EJ. Telephone: 071 388 8386.*

# ADVERTISING

## FOR THE USE OF LOCAL ASSOCIATIONS

Rates: £3 for 30 words max; £4.25 for 30-45 words;
£5.50 for 45-60 words.
Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of Link (February/March) should be submitted by Friday,15 January. Please send them to: The Editor, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

# HOLIDAY ACCOMMODATION

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

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### SUNNY TENERIFE or SCENIC NORTH WALES?

Holiday apartments at beautiful, fully accessible 'MAR Y SOL' Los Cristianos. "Brilliant, Amazing," says the BBC's Travel Show. Flights arranged, also luxury adapted bungalow (sleeps 4/5) in Mold, Clywd. Brochures: Lynne James Ltd, 7 Overpool Road, Ellesmore Port, South Wirral L66 1JW (Tel: 051 339 5316).

### ENJOY WINTER SUNSHINE AT MAR Y SOL - TENERIFE

Wheelchair accessible apartments. Heated pool with hoist. Restaurant, poolside bar. Equipment hire. Ring today for video and cheapest prices on flights and accommodation. (Tel: 0753 685718). Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx. TW19 5NX.

### SELSEY, SUSSEX

Fully-Equipped, six berth mobile home, with colour TV, ramp access, all rooms designed for wheelchair access. Site near sea, heated pool, also clubhouse and small shops. Details: Mrs C.Bugden, 27 The Grove, Sholing, Southampton, SO2 9LT. (Tel: 0703 444921)

### ISLE OF WIGHT

Isle of Wight ASBAH has a fully equipped, wheelchair accessible, two-bedroom holiday chalet. Sleeps 6 plus cot. Clubhouse, indoor heated pool, shop, etc. Site overlooks sea. Own transport advisable. Details: Mrs P Burden, 36 Sherbourne Avenue, Binstead, Ryde, Isle of Wight PO33 3PX. (Tel: 0983 564604).

### LOOE, CORNWALL

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

# FOR SALE

### ELSWICK ENVOY AUTOMATIC CAR.

X REG. MOT September 1993. Mileage 34,500. Includes wheelchair which substitutes as driving seat. Sun roof. Illuminated help sign. £1,500 for quick sale. (Tel: 0403 267150). West Sussex.

### BUY, SELL OR EXCHANGE

The Disability Equipment Register, is the direct way to buy, sell or exchange. All kinds of nursing, disability equipment or aids for disabled people. Wheelchairs, stairlifts, bath hoists, car seats etc. Telephone or write for information: The Disability Equipment Register, 4 Chatterton Road, Yate, Bristol BS17 4BJ. (Tel: 0454 318818)

### BEC STERLING SCOOTER

Three-wheeled, almost new, offers around £1,500. Mrs Broadley, 0483 (Guildford, Surrey) 232144.

### BLUE ANCHOR, NEAR MINEHEAD

Privately situated self-catering 2 or 3 bedroom bungalows, fully accessible. Fully equipped with linen. TV, video and games room, laundry, parking, playground. Splendid views of sea. Exmoor, steam railway. Contact: Lorraine or Martyn Babb, Dunster (Tel: 0643 821200) to discuss your particular needs.

### NAISH ESTATE, NEW MILTON, HAMPSHIRE

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