

Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



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Comment

AS THOUGH it was a party game, the Government is playing "pass the parcel" with our children's health and fitness for school.

For months now, ASBAH has been trying to persuade the powers-that-be to improve therapy services for children at school, so they keep as mobile as possible and better able to keep up with their classmates.

We have been pressing at ministerial level for the Department for Education and the Department of Health to cooperate in providing effective therapy cover, as well as other measures involving the health and education of the child.

At present, it is impossible to obtain a good service because neither schools nor the health-service providers think that it is

their job. They just keep passing the parcel between themselves, hoping someone else will unwrap it.

Nowadays, however, the new Code of Practice set up under the 1993 Education Act is coming into force and requires much closer liaison between all agencies and authorities involved in the education of children with special needs. The time for playing games is over.

In order to step up the pressure and expose the threadbare essentials of what is actually happening, we would like to hear of examples of children who are being failed because no single authority is taking responsibility for meeting their urgent needs for therapy.

Please contact ASBAH if you

are experiencing problems of this kind.

THE LATEST issue of our free magazine *LIFT* for disabled members - which came out at the end of November (*contact our services department at Peterborough to go on the mailing list*) - is carrying out a search for people prepared to compile their own 'Disability Diaries'.

LIFT doesn't want to know what readers ate for breakfast or even how lousy the weather was. What the magazine called for was examples of daily accounts, covering 14 consecutive days, which show clearly what examples of discrimination people came across because of their disability during this time, or indeed if there were any positives.

Disability Diaries fuelled the debate which led to all-encompassing anti-discrimination laws being enacted in the United States. Perhaps their day has arrived in Britain, too.

Tony Britton
Publicity Manager

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ASBAH is a registered charity

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Cover: role model? - Sophie Tippett joins a new generation of people setting trends in the way disability is depicted by the media. See page 11. Photo: courtesy of Motability.

Obituaries: Mrs G Brown, Mr B Hodkinson, Mr H Robinson

A FOUNDER member of Hull and District ASBAH, Mrs Gerritje Brown, died in October after a lengthy illness, aged 66. She had been secretary and mainstay of her local ASBAH since it started 27 years ago.

Mrs Brown, who was born in Rotterdam, settled in Hull after marrying her husband Charles, whom she met shortly after the Second World War while he was serving with the British Army. At the time, he was billeted at the Hook of Holland.



She started Hull ASBAH's long tradition of taking parties of members abroad on holiday, mostly - but not exclusively - to Holland where, of course, she knew all the best places to visit. These trips continued for 15 years - once with a total of 46 people travelling together, 30 of whom had disabilities.

The group holidays continued until last year, when Mrs Brown opted instead to head with members for some sunshine in Majorca.

Mrs Brown was an active supporter of a fundraising consortium of local charities in Cottingham, Hull - turning out at market stalls, Christmas card events and in costume at their Easter and Edwardian fairs.

Her husband, Charles, worked as a higher executive officer with the DSS and was made an MBE upon his retirement nine years ago. His knowledge and experience of the social security benefits system was put to good use on behalf of many members of the local association.

The couple had been married 47 years and had four children - Charles, Derkje, Carole and their youngest son, Philip, who is a member of the executive and service committees of national ASBAH. They also had nine grandchildren. Philip, the current Hull chairman, will act as secretary of Hull ASBAH at least until the end of March next year.

Among the mourners at the funeral, which took place in Hull Crematorium on 18 October at a service which filled the chapel, were many members of Hull and District ASBAH and Mr Gordon Brocklehurst, consultant neurosurgeon at Hull Royal Infirmary, who offered his unstinting support to the work of the local association.

Good Practice employment guide

A GOOD PRACTICE guide which gives a range of ideas and benchmarks to assist in the recruitment of disabled employees has been published by the Disability Resource Team. Entitled *Good Practice in Employment*, the guide gives information in the areas of: application forms, job descriptions and personal specifications, guidance notes for applicants, interviews, use of sign-language interpreters at job interviews, the role of medical advisers in the recruitment process and support at work.

The publication is also available on tape, in Braille or large print and can be obtained by sending a cheque or postal to the value of £10 (inc p & p) and made payable to The Disability Resource Team at FREEPOST NW 5774, London NW1 OYW.

BRIAN HODKINSON - It is with deep regret that we report the death of our vice-chairman who died at Whiston Hospital after a short illness on 11 November 1994, writes John Glover, chairman of St Helens and District ASBAH.

Brian was chairman of the association from 1988 until the annual meeting earlier this year and I am proud to have served as his vice-chairman during that period.

He was a "doer" rather than a "speaker" and the tasks he undertook on behalf of the association were carried out with terrier-like tenacity.

He was keen on welfare rights matters and also showed great concern that members should in no way be disadvantaged because of their disabilities.

He will be sorely missed by the association, and particularly by the committee, for all the work he did on our behalf and for his sense of humour which enlightened many a meeting. We have lost not only an enthusiastic colleague but also a friend of long standing.

HENRY ROBINSON had been ill for some time and, while it was to be expected, his death comes as a shock to those who cared about him, writes Gina Broughton, South East Region co-ordinator, ASBAH.

Henry, 29, had much to offer and worked for ASBAH as part-time receptionist/telephonist in our Upper Woburn Place offices. He was ideally suited to this type of work, having a gentle and caring manner and a wealth of good sense.

When ASBAH relocated to Peterborough, Henry went too but did not settle to his new life and shortly afterwards moved back to London. He lived at the Rosemont Road project for some time and, in his last months, he was cared for by a close friend.

Victoria launches a windsurf challenge

A FOUR-YEAR-OLD girl with spina bifida has launched *The Wash Windsurf Challenge* - a £50,000 joint fundraiser for ASBAH and the Royal National Lifeboat Institution (RNLI).

Victoria Mason, who lives near Boston, Lincolnshire, had her photo taken on board lifeboat *The Lincolnshire Poacher* at Skegness with coxswain Paul Martin and the man most involved, Olympic hopeful windsurfer Rob Barsby.

Their picture will appear on sponsor forms and posters for the event, which will soon be available from RNLI branches in the East of England and from ASBAH'S new regional centre in Peterborough.

Barsby, one of the world's top-seeded windsurfers, said: "I want to do something for a couple of superb charities before settling down to next season's Olympic qualification campaign". The 28-year-old is expected to be in the British squad at the 1996 Olympics in Atlanta.

If all goes well, Barsby's *Wash Windsurf Challenge* could make it into *The Guinness Book of Records*. The charities have asked the publishers to be on standby to record the times achieved.

"The Wash can be a choppy bit of open water at the best of times, and this is where windsurfers come into their own. We really move in conditions which can leave small craft floundering", said Rob, of Husbands Bosworth, near Market Harborough, Leicestershire.



Victoria on board *The Lincolnshire Poacher* with Rob Barsby and Paul Martin.

He plans to complete each 15-mile leg of the voyage between Skegness and Hunstanton in under 90 minutes - leaving plenty of time to enjoy the rest of the Easter holiday.

Rob's windsurfing performance in this summer's top tournament, the four-nations North Sea Cup, left him the winner overall and in third place in the international ratings for his class.

Money raised from *The Wash Windsurf Challenge* will go towards the RNLI's Humber Lifeboat Appeal and ASBAH'S work supporting young people with spina bifida and their families in the East of England.

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All dressed up - and somewhere to go!

A NEW guide to choosing clothes and useful dressing techniques for disabled people called *All Dressed Up*. . . is more than just a manual - thanks to a couple of hundred helpful line-drawings by Jane Peart.

The book was also published by the Disabled Living Foundation - so you cannot get much better quality control than that.

The book has been produced with help from J D Williams, a Manchester-based company specialising in clothing and footwear for elderly people and people with disabilities.

It includes sections on the most useful styles, features, adaptations and gadgets, as well as providing a step-by-step guide to the most effective techniques for putting on and taking off clothes.

Information on clothing for toileting and temporary disabilities, as well as essential background information to assist people who want to teach dressing skills and techniques, is also included.

All Dressed Up. . . costs £4.95, including p & p, and is available from the DLF, 380-384 Harrow Road, London W9 2HU. ASBAH's information department has four copies available for loan.

Thanks, Pudsey!



AGAINST the trend of a decline in giving to the *BBC Children in Need* appeal, ASBAH's share of the proceeds from last year's TV and radio appeal held up well - being pegged at £24,000, the same amount as the record total we received last year.

"I'm convinced that we have been successful again this year because we account so thoroughly for every penny spent, and give very detailed reports to the trustees", said senior services manager Teresa Cole.

From last year's allocation of *BBC Children in Need* money, ASBAH gave 97 grants to young people aged 18 and under throughout England, Wales and Northern Ireland.

Many of these youngsters are prevented by problems with their mobility and hand-eye co-ordination from competing on a level playing field with other children in their age-group, and need specialist equipment to be able to boost their performance.

Examples were: £100 towards the cost of a wheelchair to a 17-year-old girl whose mother has trouble moving her because of a bad back; £150 towards a trike to enable a five-year-old to get out and play with her friends; £300 towards a specialised computer to enable a teenage girl who is also blind and deaf to write down her thoughts; and £150 towards a double buggy for a three-year-old girl, whose

mum was due to have another baby.

The family of a girl aged three was given £250-worth of garden toys so their daughter could play outside in her mainly concrete backyard. £400 went to a six-year-old with walking problems so she could have an exercise bike.

Thanks also to a cut-price deal negotiated with Panasonic, ASBAH was also able to spend some of the *BBC Children in Need* money by buying 15 lap-top word-processors for use by school children. These children are in schools which cannot afford to let them use personal-use computers to overcome writing difficulties. The ASBAH computers are for use in the classroom and for home-work.

Money has also been given to ASBAH from the television appeal to help with two very worthwhile projects - details to be announced soon.

Our South East region was given £3,650 to spend on a music and drama weekend - with one group of children taking part in music workshops and a second in drama workshops. As a finale, both groups will join for a stage show.

Our Northern Ireland team has been given £1,350 to run a residential course in wheelchair-handling and mobility skills.

Try this supply service - free to LINK readers

We would like to remind readers of a free service being offered to them by AlphaMed Ltd - reputable suppliers of continence products and other medical equipment. They will make a donation to ASBAH for every prescription order that comes their way through ASBAH's introduction. If you want to try the service - described more fully in LINK No 153 - obtain a Freepost envelope from our services department, tel 01733-555988. Then, when you obtain your next prescription for continence or medical supplies, pop it off to Alphamed in the envelope. DO NOT SEND PRESCRIPTIONS FOR DRUGS OR MEDICINES. Alphamed will dispatch your goods on the day they receive your prescription for delivery within 48 hours, and send more Freepost envelopes in case you want to use them again. You can phone them free on 0800-515317 with any questions.

Guide to effective communication

WALSALL Information Federation has just launched a guide called *A Code of Practice - Information Provision for Disabled People*.

Walsall has produced the guide to advise groups and organisations on how best to communicate effectively with disabled people. It explains which communication barriers are encountered by people with different types of impairments and the range of equipment and services that can be used to overcome these barriers.

Copies from Samantha Healey, Walsall Information Federation, Room 3, Whitehall Infants School, West Street, Walsall, West Midlands WS1 4BQ. Please enclose A4 SAE.

A SURVEY by Northern Ireland Employers' Forum on Disability shows local firms are falling short of the 3% quota set for employing disabled people. On average, only 1.5% of employees in all companies had disabilities and only 0.7% were registered disabled. The survey coincided with the launch in October of a campaign by the umbrella group *Rights Now!* to ban discrimination in the Province.



Norma drives Iris wild with joy!

PRIME MINISTER's wife Norma Major drove a brand-new, £10,500 car into the life of ASBAH telesales rep Iris Rootham recently.

And the reason for the VIP delivery of the Vauxhall Astra car, with the number-plate ARC 1? Iris won the car in a raffle run by the Arthritis and Rheumatism Council, of which John and Norma Major are top supporters. All Iris laid out was 20p for one ticket.

"I was thrilled", purred Iris - pictured topping up the tank at a Vauxhall dealership near Peterborough. "I've never had a new car before, and I have had 2,000 miles of trouble-free motoring in it since then. It's been great.

"And Norma Major was lovely, too - really down to earth and friendly!"

Help & Advice

Members seeking help and advice on any matters should make initial contact with ASBAH as follows:

London, Surrey, Kent, Sussex

123 East Barnet Road, New Barnet, Herts EN4 8RF. Tel: (0181) 449 0475
Regional Co-ordinator: Gina Broughton, BA (Hons).

Lincs, Cambs, Leics, Notts, Northants, Norfolk, Sussex, Essex, Herts, Beds

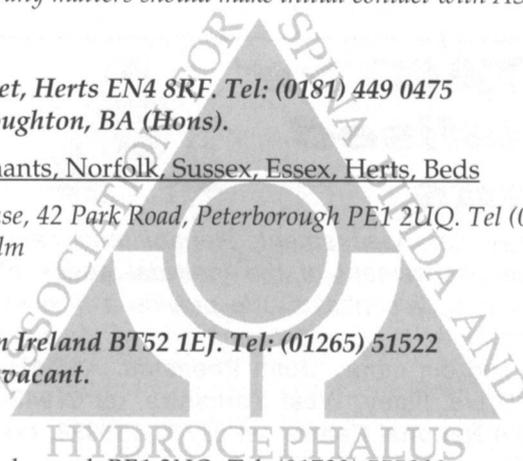
Eastern Region Office, ASBAH House, 42 Park Road, Peterborough PE1 2UQ. Tel (01733) 555988
Regional Co-ordinator: Mary Malcolm

Northern Ireland

73 New Row, Coleraine, Northern Ireland BT52 1EJ. Tel: (01265) 51522
Regional Co-ordinator: Position vacant.

Rest of England and Wales

National Centre, 42 Park Road, Peterborough PE1 2UQ. Tel: (01733) 555988.



International Motor Show

John Naudé enjoys his day out at Birmingham



I had the pleasure of attending this year's 70th International Motor Show at the Birmingham National Exhibition Centre on Tuesday, 25th October. This was their special day for disabled people, called Mobility Day.

This was my first time at the Motor Show and I was amazed at the sheer size of it. I had heard that the best thing to do was to buy a programme and use the plan of the exhibition to stop me from getting lost and confused.

In this article I would like to mention things like 0-60, torque ratios and brake horse power but I am afraid all that stuff goes over my head. My main concerns are the size of the boot, does it come with an automatic gearbox, comfort and design. (This is probably just a little bit better than if it is a nice colour!)

I was amazed at how busy the show was and how many companies were there. I was also

pleased to see so many disabled people roaming around the stands asking questions of the manufacturers about the design of cars for disabled people. When I consider how many cars were on show, and how many hatchbacks there were, it surprises me why so many of them have such a big lip into the boot.

The new cars to look out for are the Vauxhall Tigre, a small sporty looking car with quite a reasonable amount of space in the boot considering it is such a small car. Unfortunately, Vauxhall has no immediate plans to introduce a automatic gearbox in the near future but maybe in the not too distant future. Another car which at some point will also come out in an automatic gearbox is the new Volkswagen Polo (pictured). It has a deep boot which would suit a folded wheelchair or smallish rigid-framed wheelchair (without the parcel shelf in the car). Ford told me they are likely to bring out

the Ford Escort with an automatic gearbox some time next year.

It was good to see that most stands had ramped access, although I was disappointed to see that Mazda exhibited all the top of the range cars on the ground level with the range of smaller cars up two large steps. I mentioned this to a representative who assured me this was not of their doing, but a problem caused by someone else. Hopefully, next time it won't be a problem.

The Motor Show is a good time to look and explore the cars all in one go. If you however are interested in a Porsche or one or two other "flashy" cars, then be prepared to climb stairs. They don't expect wheelchair-users to drive these sort of cars. Also discount rumours that the new Ferrari will be on the Motability scheme, with just a small deposit!

John Naudé is ASBAH's mobility adviser.

START-ing up!

AT THE foot of this page, we run an advertisement for our new START service which will also appear in the *Social Services Yearbook 1995*.

The advert is aimed primarily at purchasers of services within the social services departments of local authorities, who need to be told that ASBAH is structured to help them meet their obligations towards people with spina bifida and/or hydrocephalus under the Community Care arrangements, by being in a position to provide detailed and careful assessments of individual needs. This expert knowledge and experience is missing in many SSDs.

The reference to price does not affect ASBAH's unswerving commitment to providing free services to our service-users at the point of delivery.

Contact **START** for your specialised assessments



START is our Service Team for Assessment, Rehabilitation and Training, specialising in the assessment of the individual needs of people with spina bifida and/or hydrocephalus. We provide a flexible, quality service - delivered promptly to your doorstep and at the right price. Please contact me to find out more: **Joan Pheasant, ASBAH, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorkshire, tel 01943-603013, or through ASBAH's National Centre, tel 01733-555988, fax 01733-555985. Registered Charity 249338.**

Margaret pulls up the stumps on fieldwork!



AN ASBAH fieldworker, who stayed in post well beyond state retirement age when she found out there would be insufficient funds to replace her, has finally called it a day.

Margaret Holmes (63) became fieldworker for Bromley and Bexley seven years ago, having previously worked in a local council treasurer's department as principal valuation officer.

Having spina bifida herself, she had been previously involved in the South Thames Local Association becoming its chairman for five years. She then became an ASBAH fieldworker in the area.

She said: "I was going to do the job until I was 60, but found that ASBAH wouldn't be able to replace me if I left so I kept going for another three years."

An avid cricket fan, she and partner Geoff Harrison - who is treasurer of South Thames ASBAH - will be spending the first three weeks of her retirement in Zimbabwe on safari and a cricket tour.

They will be travelling with their favourite team, the Gloucestershire Gypsies - Margaret keeping tabs on the games as a scorer while Geoff doffs a Panama hat as an umpire.

She said: "I've always been interested in cricket - ever since my father used to take me to watch matches before the war. I was brought up with the game."

On their return to Britain, Mrs Holmes intends staying involved in the local association, a local bereavement group, and the church - as well as running courses for cricket scorers.

Changes in Northern Ireland and Peterborough

AN EX-SOCIAL worker, who has been an ASBAH fieldworker for more than three years, has been appointed as one of our regional co-ordinators.

Margaret Young (52) was selected from four shortlisted candidates for the job in Northern Ireland Region. She was the only internal candidate, and succeeds Meta Harvey.

Margaret joined ASBAH as fieldworker for South & East Belfast & Ards Peninsula after 15 years as a social worker, specialising in physical disability.

She spent four years at a special school where almost half of the pupils had spina bifida and hydrocephalus. Eleven years were then spent as social worker in a multi-disciplinary team, based at an assessment centre dealing with children with any sort of development problem from all over Northern Ireland.

Of her new job, which starts on 1 December, Margaret said: "I'll be sorry to give up direct contact with

families. But I see my new role as an opportunity to develop services and look at the overall picture and be involved in the planning for the future."

The fieldworker vacancy left by Margaret Young will be filled.

At Peterborough, we also say farewell to Paul Wootton who leaves at Christmas after more than three years as fundraising/business liaison manager.

Paul (55) is to help manage and direct a young group of publishing

companies based in Peterborough.

Paul joined ASBAH from the finance world in 1992, having trained as an engineer and then spending 20 years with companies in the Midland Bank Group, progressing through management. A published writer, he lives with his wife Trish in Peterborough. The couple have two adult children.

ASBAH is to slightly restructure its fund-raising operation, and is advertising for a senior appeals manager.

'PEACE IS BREAKING OUT'

A NEW era of peace seems to have broken out in Northern Ireland, said Meta Harvey, who in October resigned as ASBAH's regional co-ordinator in Northern Ireland.

With the scaling back of paramilitary violence, she said: "It's very calm here at the moment and, while there are no guarantees that it will continue, it is a real pleasure after so long to walk down the street without seeing police and soldiers expecting trouble."

Mrs Harvey has become SENSE's regional services manager in Northern Ireland after three years with ASBAH. She was working as a teacher in the prison service just before becoming ASBAH's education adviser in the Province - shortly before taking over the regional co-ordinator's reins from June Kerr.

Disability On Film *By Paul Darke*

NOT MANY books in circulation deal with disability and the cinema, so it is especially rewarding to come across a new publication that not only breaks new ground in this area but also excites and stimulates the readers (and has plenty of pictures to keep plebs like me happy).

I unreservedly recommend that all people with disabilities go out and buy (or order as will most probably be the case) Martin F Norden's *The Cinema of Isolation: A History of Physical Disability in the Movies*. Its analysis, and discussions, of all Hollywood films - plus many non-American movies - that have a physically disabled character in is bewildering in its scope. No movie is missed and the analysis of each of them is eclectic, academic and anecdotal, which, in turn, makes it highly informative, educational and readable.

Norden, with considerable skill and entertainment, clearly shows the derogatory road that images of disability have gone down; whilst highlighting different eras' specific concerns and pressures. For example, Norden conclusively shows that in the immediate aftermath of World War II disability imagery improved (ie *The Best Years of Our Lives* [1946] directed by William Wyler) due to the involvement of that war's veterans and the subsequent liberal political climate.

Norden then, equally persuasively, reveals how the "Cold War" climate - and the Communist witch-hunts - left many of the progressive film makers out in the cold in a repressive and conservative political climate. Consequently, these combined events heralded the return of the one-dimensional disabled character as either a "sweet innocent" or "obsessive avenger."

The book covers not only "talkies" but silent as well including the very earliest one-reelers, with glorious titles such as *The Cripple's Wedding*, *The Deaf-Mutes' Ball*, *The Legless Runner*, *The Little Cripple* and, my favourite title, from a 1908 short, titled *The Paralytic's Vengeance*. The book also covers very new films such as *Passion Fish*, *The Waterdance* and *The Fugitive*.

Disabled people buy this book, but it should be compulsory reading for all film-makers, critics and scholars - those people most responsible for perpetuating and ignoring the treatment of people with disabilities in movies. I can but applaud Rutgers University Press for publishing this book as, sadly, it is as needed now as it ever has been. Though the £16.95 for the paper back (£48 for hardback!) is a little on the high side, it's a must.

Martin F Norden, The Cinema of Isolation: A History of Physical Disability in the Movies, Rutgers University Press (1994).

Equal rights for disabled people demanded in Gallup Poll

AN OVERWHELMING majority of the British people believe that the Government is not doing enough for disabled people, according to a national survey undertaken by Gallup for RADAR. Furthermore, it is an issue that affects the way many people are likely to vote.

The poll showed that 80% of Britons felt that the Government was not doing enough to ensure equal rights and opportunities for disabled people.

And - highlighting the strength of feeling behind this issue - 56% said they would be more likely to vote for a political party that brought in legislation which made it illegal to discriminate against disabled people - compared with just 3% who said they would be less likely to vote for a party introducing such legislation.

RADAR commissioned the Gallup survey to help establish public opinion on the subject of legislation and civil rights for disabled people, at a time when

the Government's consultation document *Measures to Tackle Discrimination Against Disabled People* was being debated.

The results of the survey - carried out between 2 and 7 September when 1,056 men and women throughout Great Britain were questioned - were unequivocal.

When asked about legislation, eight out of 10 people said they believed the Government should introduce legislation to outlaw discrimination against disabled people.

The depth of public support for effective measures to improve the lives of disabled people in Britain were also highlighted by the survey. Huge majorities of people questioned felt it was very important that public transport and all buildings were accessible. Two-thirds said it was very important that the Government promote integrated education for disabled students.

Cover-girl Sophie

FOR most nine-year-olds, the dream of becoming a cover-girl and following in the footsteps of Naomi, Claudia and Cindy remains just a dream.

But for Sophie Tippett, starring on her own front cover is just the start of what could be an exciting career.

What makes Sophie's story particularly special is the fact that, as well as being extremely pretty, she is a natural in front of the camera.

Sophie has spina bifida and hydrocephalus, and uses a wheelchair to get around. Her parents drive a Motability Vauxhall Astra on her behalf, and it was by entering photographs of their daughter in a "Motability Smile" competition that Sophie became a cover girl.

Mum Jan explained: "Sophie is very photogenic and has always wanted to be a pop star."

Although Sophie did not win the competition, she received a letter saying Motability wanted to use her picture on the front cover of the magazine.

She and her mum travelled to London to a studio in which promotional photographs have been taken of bands like East 17, Take That, Bad Boys Inc.

Mrs Tippett said: "There was a lot of waiting around while they got the right lighting and background but Sophie didn't complain. Then she was told to look a certain way and she'd shine for the camera and shine again. They said she was a natural."

But Sophie's stardom didn't end there. After returning home to Sheffield, a phone call from Motability said Vauxhall liked the

continued on page 12



Disabled models in demand

TALENTED people "with the right look" are being sought by a Birmingham-based agency which will help them carve out a career in the lucrative world of modelling.

The Louise Dyson Agency, based in Birmingham, started its quest for disabled models after a client realised it should advertise its mobility equipment using real-life wheelchair users - rather than able-bodied people pretending to be disabled.

So, agency and client got together to organise a national modelling competition to find the best disabled people to work with.

The competition attracted 600 entries, 100 of which were considered of high enough standard to be interviewed.

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Sophie Tippett, from page 11

photos so much they wanted to take more and conduct an interview at the Motor Show.

Mrs Tippett said: "On the day we went to the Motor Show, Sophie had the 'flu so wasn't as sparkling as she could have been. Again we sat waiting a long time as there were two takes."

At the end of an exhausting day, Sophie told her mother she would not be a model again unless it was something different.

Once home they received yet another phone call, this time from Whizz-Kidz - supplier of Sophie's wheelchair - who wanted to interview her for the Children In Need Appeal.

Mrs Tippett said: "Sophie wants to be a model and do a twirl but she walks with sticks and callipers, and I don't know how other people would respond.

"I'm all for promoting people with wheelchairs and mobility aids, but I'm not sure what Sophie really wants. Modelling looks so easy, but I don't think she realised how hard work it would be."

It's not the first time of fame for mother and daughter who starred on a front cover of *Mother & Baby* magazine when Sophie was two years old.

Louise Dyson's modelling agency, from page 11

A dozen men and women were eventually selected and trained, some of whom made BBC Breakfast Time recently when they wheeled themselves down the catwalk at the Naidex Exhibition modelling clothes from Next.

Louise Dyson, who owns the agency, believes opportunities for disabled models exist not just in the disabled market but in mainstream advertising too.

She said: "There is really no reason why a model with the required looks cannot advertise all sorts of products from shampoo to chocolate bars, while sitting, perhaps, in a wheelchair.

"Disabled people are consumers and it is about time they were represented somewhere in marketing campaigns."

However, she offered a word of warning to those thinking of becoming a model.

She said: "Modelling is still notoriously difficult to break into and it is unlikely to be much easier for disabled models. You will have to look outstanding and you will, of course, require the stamina and tenacity to travel from one studio to the next, suitably equipped and looking exactly right when you arrive for each session."

At times, Louise has been less than impressed with the motivation of some disabled models, who have proved unreliable at keeping appointments or who expect everything to be done for them.

Louise said: "I want to promote everybody, whether they have a disability or not, but the only way I can do this is for them to get their act together."

She added: "We can offer advice and help to photographers, concerning access and assistance on set.

"The idea is that clients must be able to achieve at least the same results as those expected of able-bodied models - and at no extra cost or hassle to themselves."

For more details about modelling as a career contact the Louise Dyson Agency Ltd, 95 Spencer Street, The Jewellery Quarter, Birmingham, B18 6DA. Telephone (0121) 554 7878.

Mark's a male model



THIRTY-six-year-old wheelchair-user Mark Agar takes up modelling opportunities as they arise but still keeps

his full-time office job.

He started modelling when his employer, Sunrise Medical, wanted disabled rather than able-bodied people to show off its mobility equipment. That was several years ago now and he continues to take

modelling jobs when they are offered.

He entered the *Model In A Million* competition and, although he did not come anywhere, remains on the books of the Louise Dyson Agency in case any work arises.

Mark, who has spina bifida and lives in Edgbaston, Birmingham, said one of the most important qualities needed by disabled people to become models was confidence.

He said: "Confidence doesn't happen straight away with

wheelchair users and it takes a lot for them to take that first move."

Other qualities needed, he said, depended on the type of modelling.

"You need a reasonable physique and look smart. If you're going to model clothes you need to have a good fitting structure."

The work Mark has done for Sunrise Medical, one of the biggest independent suppliers of mobility equipment, has included promotional videos and photographs for brochures.

Sandra's Wheel Challenge

Liz Cawthorne reports on a disabled woman who rode 200 miles around Ireland on a specially adapted cycle for charity. And she enjoyed it so much she is already planning her next three-wheeled challenge.

A 30-year-old woman with spina bifida and hydrocephalus who completed a 200-mile cycle ride hopes her achievement will inspire others.

Sandra Cole (pictured), who has difficulty walking, trained for three months to be strong enough in the upper part of her body to complete the Cork-to-Kerry run on a specially adapted cycle.

The £2,000 machine moves by rotating the handlebars, attached to the chain, while keeping the legs still. It was made by Chevron of Liverpool and brought for her by the Venture Abilities Trust.

The Ireland achievement - completed in September along with 130 able bodied people - has, in part, made up for a knock in confidence Sandra experienced when she lost her job just over a year ago.

As someone with hydrocephalus she has a certain level of learning difficulty and admits her output is about 30% of an able-bodied person.

She took part in the sponsored cycle ride because of her interest in "Third World" issues and all money raised will go to VSO - Voluntary Service Overseas.

Sandra, of Southampton, said: "I got involved with VSO five years ago as a continuation of my Duke of Edinburgh Gold Award which was covered in *LINK*. I would love to go abroad with VSO but don't have the academic qualifications so I decided to get involved on the fundraising side."

She added: "It took me a long time to find anyone interested in helping me to complete the VSO Charity Bike Ride, but eventually Venture Abilities Trust wrote back



to me and said they could help me find a cycle."

Sandra enjoyed the cycle ride so much - despite feeling tired and the bike suffering a technical hitch on the first day - she is already planning the next one.

She said: "I want to cycle from Land's End to John O'Groats for VSO and another charity in 1996 but I'll need people willing to act as a back-up team and medical team and sponsorship for accommodation on the route."

"I hope my cycle ride in Ireland will inspire others. What with losing our jobs and all the other things we have to put up with, I hope people in a similar situation to me will pick themselves up and get going again.

"My philosophy is everyone has something they are good at and I enjoy a challenge. It's no fun sitting around feeling sorry for yourself."

■ Sandra is looking to raise thousands of pounds for VSO from the Cork-to-Kerry ride, as well as raising money to buy the special cycle from Venture Abilities Trust.

Anyone who would like to contribute to the VSO total should send a cheque to: Helen Castle, VSO, 317 Putney Bridge Road, London, SW15 2PN, saying the money is in support of Sandra Cole's cycle ride.

Adult disability service is not the one and only

JUST in case readers gained an impression from the headline *At last... An Adult Disability Service* in the August *LINK* that Dr Richard Morgan's clinic at the Chelsea and Westminster Hospital is the only one in the country, we have been reminded by Sister Deirdre Browning of the adult service for people with spina bifida and hydrocephalus at the Chailey Heritage centre, East Sussex.

This clinic, usually available on alternate Friday mornings, has been running with the help of Sussex ASBAH since 1984. Consultants, specialist nurses,

therapists and a fieldworker are all at hand. Hospital transport is also available by prior arrangement.

Sister Browning adds that Chailey's rehabilitation engineers frequently come to the clinic to sort out seating problems, and also orthotics. "This means that boots and appliances can be sorted at the time of appointment".

LINK hopes to carry a full feature on the work of the adult clinic in a future issue. Watch out for Liz Cawthorne's report in February or April.

Rolling back through

WHEELS and chairs have been around a long time - since about 4,000 BC. But it was a long time before anyone had the bright idea of putting the two together.

Research by Herman L Kamenez, first published in the *American Journal of the History of Medicine* in 1969, came up with China as the source for the very first picture of a wheeled chair. A stone sarcophagus, dated around 525 AD, shows a pious youth attending an older man who seems to be squatting in an elegant - if uncushioned - three-wheeler. . . a sort of platform on wheels.

Until then, and for long afterwards, the standard transport for sick and wounded people was simply a litter. For people who preferred to sit up, the sedan chair dates back to the Romans.

The Chinese, according to Dr Kamenez, can also be thanked for the final variation on the theme - the wheelbarrow. Invented by the Chinese in the third century AD, it took until the twelfth century to

get to Europe, via the Crusades.

Human ingenuity devised lots of different ways to use these basic mechanisms. Often they were invented and constructed by the users themselves, a theme that continues today.

For instance, reports Dr Kamenez, you could simply put rollers under a standard household chair. By the sixteenth century, these "chairs of commodity" could have head wings, arm rests, and even a reclining back, worked on a ratchet.

The ultimate example might be the "gout chair" built for Philip II of Spain in 1595, with four wheels and adjustable back, leg rest and arm rests.

A century later, there were 20 assorted rolling chairs at the Palace of Versailles, and the Sun King, Louis XIV, spent whole days in his "roulette".

Less regal users had an interest in being self-propelled. Dr Kamenez finds several designs in seventeenth century Germany.

The most influential seems to have been the low-slung model, home-made by a paraplegic watchmaker in 1655. "His choice of the mechanism to turn the wheels was certainly no coincidence," says Dr Kamenez. "Faithful to his trade, he used cog-wheels turned by two cranks.

"Until today, over 300 years later, cranks have continued to be used to turn the small wheels of chairs."

Meanwhile, the good old sedan continued to be the choice for simplicity. The nuisance was, of course, that you needed two people to carry it. A bright Frenchman, Dupin, in 1669 thought of subtracting one footman and substituting a front wheel (thus marrying the sedan to the wheelbarrow).

The resulting hybrid, Dr Kamenez reports, sprouted lots of variations - notably an open front, and a steering rod for the occupant. And so, inexorably, was born that solid, unstoppable institution. . . the Bath chair.

Its inventor proper was probably one John Dawson of Bath, who in 1798 actually called himself a "wheel-chair maker". And what a chair! Typically, said Dr Kamenez, the Bath chair had two large wheels at the back, a smaller one at the front, a steering rod and an attendant to do the actual pushing (or pulling). Framework and wheels were of iron, topped by a canvas hood for the rain.

A parallel development for indoors was the midline-swivelling wheel, and chairs with wheels large enough to be turned by the user.

Back to basics: the wheelbarrow dates back to third century China. Picture: Mary Evans Library



time

A brief history of the wheelchair by Laura Swaffield. This article first appeared in *Therapy Weekly*.

Wheel patterns varied, as did the chair itself from wood to wicker, and accessories like footboards came and went. But the main development was lighter construction and bigger wheels. By the late nineteenth century, says Dr Kamenez, some US models had a hand trim on the wheels.



The Bath chair: there has never been anything quite like it - or has there?

Picture: Mary Evans Library

At this point, he says, the impulse for further progress came from a new element - the bicycle. When bicycle wheels changed from wood to wire spokes, so did wheelchair wheels. When rubber tyres came in, they went on to wheelchairs as well.

And, ever since, the sporting world has been the driving force behind developments in wheelchairs.

Peter Carruthers of Bromakin Wheelchairs - himself the 100m gold medallist at the Seoul Paralympics - explains: "Most the recent developments began with wheelchair sports, particularly basketball, which began in about 1945. The new ability to synthesize penicillin, which came during the war, suddenly meant that more people with spinal injuries were surviving.

"Previously, people might have had to use wheelchairs for other things, but they weren't primarily for people who just had paralysis of the lower limbs.

"Next, Ludwig Guttman at Stoke Mandeville started using sports as rehabilitation.

"The first lightweight chairs were made in California in the seventies, because it was the centre of the aircraft industry. Aluminium was being used to manufacture planes, and was readily available. So were devices like quick-release pins, fitted to

planes to make servicing and loading easier. Polyurethane parts, and small front casters, came in around the late seventies. They were originally developed for skateboards!"

At this point, the wheel started to come full circle, says Ric Cassell, another wheelchair racer. "Bright sparks added other developments, like box frames and a different camber on the back wheels. In the early eighties, a couple of tetraplegics in the US started to use basketball chairs as a basis for everyday wheelchairs.

"People bought them, and realised they were good for playing sports in. Now, a lot of people call a lightweight chair a sports chair. I have to explain, even to therapists, that lightweight chairs aren't sports chairs, but are designed to maximise performance. They allow, for instance, a high-level tetraplegic to go out in a manual.

"The folding chair is outsold now in the UK by rigid chairs, which built in titanium can be as light as six pounds. A tetraplegic can just lift it into his passenger seat.

"In the US, in particular, they have developed an extremely good range of chairs with accessories that make them suitable for an enormous range of people - effectively, custom chairs.

"It is not good enough to fit the customer to the nearest size in

stock. An inch difference in the seat width, or the sling depth, or the frame depth, can make all the difference. And this is the real secret.

"People often are tempted to buy all kinds of expensive accessories like arm rests. I tell them that these are not needed if the chair is well enough adjusted to the user."

Detailed experience, says Mr Cassell, may be the key. But it is often in short supply.

"Some PTs and OTs have a specific interest in wheelchairs, but that's not the way the system has been set up in this country. The job is not necessarily given to someone who has any more than basic training."

And, in the country where the last major development boost started, the United States, Ed Rowan, of Eastern Paralyzed Veterans Association wheelchair services, looks back and sees a return to essentials.

Disabled in the Korean War, he was issued with a 70lb chair, with heavy duty wheels and axles, which was nearly half his own weight of 160 lb. Since then, he says, he has gained weight and the chairs have lost weight! The impetus, he confirms, came from post-war sport, in the US very much pioneered by war veterans.

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"They played, especially basketball, in those old clunkers, right through the fifties and sixties. Civilians started joining in the games. Then people started experimenting.

"The angled-out camber, for instance, came from a guy called Bud Rumble in Detroit, who developed it in his garage and then started selling to teams all over."

Meanwhile, says Mr Rowan, a quite different development took place - power chairs. "You never saw a power chair in the vets' hospitals in the sixties. They were resisted for a long time. The authorities thought people would get run over.

"They were very jerky at first, too. Now, I almost feel they are over-sophisticated.

"The trouble is, things have got so

refined that you get more breakdowns. I went to a conference in South Carolina recently where they said that power chairs are down for 25 per cent of the time."

Power chairs, all the same, have brought a whole new dimension of independence. The cheapest option is the scooter, first seen in the US in the sixties. Front-wheel drive models were supplemented by more powerful rear-wheel drive versions in the eighties.

Essentially a seat mounted on a wheeled platform with a tiller control, the scooter brought extra power to the growing number of disabled people with reasonably good upper-body function.

Meanwhile, powered wheelchairs have forged ahead in the past 20 years. The jerky, old joystick

control boxes have gone, and so have belt and chain-driven models. Instead, a huge choice of options (for those with the money) allows anything from individually programmed controls to stair-climbing.

A less space-age, but equally valid, advantage of the powered wheelchair over the scooter is its ability to take sophisticated and/or customised seating. And seating itself has progressed quite dramatically in the past 20 years on the twin fronts of posture control and pressure area relief.

Next move? Who knows? The message seems to be that, whatever technical wonders come along, they need to remain centered on the real needs of the human being in the chair.

Laura Swaffield is a freelance journalist.

And now . . . get wheely up-to-date

**Advice on buying a wheelchair today by
John Naudé, ASBAH mobility adviser**

ONE OF the good things about the development in wheelchairs is that it has given wheelchair users more choice, instead of accepting whichever one the wheelchair service decided to provide.

Before you contemplate buying a wheelchair, try and get it through your local wheelchair service, or through your local PACT team at the employment centre. (This may be through the *Access to Work* scheme). The important thing is to approach them once you know what wheelchair it is you NEED.

Don't say you need it for sport, that does not count. Say you need it for climbing kerbs, for example.

The problem maybe is that you may not know what wheelchair you need or want. The most important thing to do is to ask yourself what are my needs? It is very easy to be

tempted by the glossy brochures, and the brilliant colour of the chair. Colour is important, but there are many other things to think about first.

Think about what you want to do with the wheelchair. Are you going to use it around the house and occasionally going to the shops, or are you wanting to go abseiling or cross-country trekking? How strong does it need to be? Is it likely to get thrown about playing sports? Is it going to be used mainly on pavements or do you live in the country and go over rough terrain? How light does the wheelchair have to be?

If you are unable to lift the standard wheelchair into your car, might it be worth considering a made-to-measure wheelchair - even if it means spending more money? You also need to think

about the size of car you drive or your family and friends drive. There are a vast amount of wheelchairs on the market, try as many out for yourself. See what the differences are in each wheelchair.

The whole thing about choosing a wheelchair is to make sure you know what you need. It is very similar to buying a car. You think of what you are going to use it for, short or long journeys. Does it need to be a large car or a small nippy thing. How much comfort do you want from it? Does it need to be quite big for you? Then you should think about the servicing. How good is the company you are buying from and do they give good after-sales services?

You are the buyer - so you can ask as many questions as you would like to ask.

If you are still unsure, then please feel free to give me a ring at National Office. Don't go spending lots of money on a wheelchair if you are not absolutely sure that it is the right one for you.

1994 AGM, NATIONAL ASBAH – FOUR-PAGE FEATURE

LINKS have been forged between ASBAH and the local authority directors who head up social services departments across the country.

Roy Taylor, (pictured right), director of social services for the Royal Borough of Kingston-upon-Thames and chair of the Association of Directors of Social Services disabilities committee, addressing the AGM, said that the initial contact was made after he had heard about the closure of Five Oaks on Radio 4's *Does He Take Sugar?* programme.

After meeting ASBAH's executive director, Andrew Russell, he was invited to speak at our annual meeting.

In his presentation at the AGM, Mr Taylor looked at Community Care and the impact it was having on service provision for disabled people.

Why Community Care?

In the 10 years leading up to 1989, Government spending on residential care for disabled and elderly people exploded from £10 million to £1.5 billion.

This massive increase in spending probably played a significant part in the Government introducing

ASBAH LINKS WITH LOCAL AUTHORITY SERVICE DIRECTORS



legislation relating access to residential care to need and limiting the cash level to 1989 levels (except for inflation).

The emphasis on service provision has been transferred from residential care to home care, day care and respite care. There is also a shift in who is the service provider from health authority to a wider range of organisations - the private sector and charities - and a move from a fragmented to a more co-ordinated approach.

The main difficulty in implementing Community Care has been changeovers in staff and the time it takes new staff to become familiar with all the relevant legislation, contained in some half a dozen Acts of Parliament.

Another difficulty to overcome has been tackling the position disability has in the general

pecking order of public services provided by local authorities.

Care Management Roles

1. Assessment of needs.
2. Co-ordination of special assessments.
3. Agree a written care plan.
4. Completing a complex needs assessment form and service plan.
5. Commission services.
6. Co-ordinate package of care.
7. Review services.

Mr Taylor said: "Most social services departments are split between purchasing and providing units and the jury is out as to whether these activities should be split or combined.

"A small amount of staff means many carry out two roles."

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Director reports on a full, productive year. . .



NEW challenges and past achievements were spotlighted in a report given by executive director Andrew Russell (pictured left).

As well as maintaining an individual, caring approach, he said ASBAH was a specialised organisation with a lot of knowledge and experience. It stayed close to its roots through local associations, members, clients and committees.

It has professional staff who are highly motivated; many contacts with outside experts; and effective fundraising teams, who have organised a wide range of appeals.

Among the challenges faced by ASBAH, Mr Russell said, was to place disability higher on the public agenda, and on the agenda of public services. Spina bifida and hydrocephalus should be at the forefront so that appropriate services are made available to clients and families.

Other challenges were to develop fundraising so that ASBAH could extend its services, publicity and research; and to market these services so they could be extended and more effective.

In confronting these challenges, Mr Russell said, perhaps the most important factor was "getting the message across" through study days, giving advice,

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SOCIAL SERVICES

What has changed?

More people are demanding care services, which is good news, but in many cases the amount of money in the pot has gone down.

Mr Taylor said: "I have lost £2 million in my budget in the Royal Borough of Kingston because of spending cuts."

Progress in the first year of Community Care

According to Arthritis Care, the assessment process is financially-driven rather than needs-led. The charity, which has one of the largest memberships in Britain, says most local authorities do not have the staff to carry out the assessment needs necessary.

RADAR - the Royal Association for Disability and Rehabilitation - says that consultation, collaboration, co-operation and communication are sadly lacking in many local authorities.

And The Carers' National Association says most carers have noticed no improvement since the introduction of Community Care.

Mr Taylor cited the case of a target figure of 117,000 new assessments of elderly and disabled people for 1992/93 actually reaching half a million.

Problems of Community Care

- The language is difficult to understand.
- Building access is inadequate.
- People are unsure what their entitlement is and do not know what it is all about. Many are fearful of saying anything negative about a service in case it is taken away.
- Not enough occupational therapists.
- Charges are now having to be made for services when previously they were free.
- Increasing costs of transport.
- Unmet needs.

What can be done to improve things?

- More money.
- More involvement of disabled people.
- Use less jargon and explain terms.
- Publicising complaints.
- Saying that advocacy is all right.
- Providing disability awareness training.
- Working with other groups for disabled people like ASBAH.

While he is chairman of the disabilities committee, Mr Taylor wants to raise the profile of disabled people and press Government to establish a disability team to go around the country and demonstrate what good practice is."

He said: "It's a difficult time financially but there are staff up and down the country who are sensitive to disability."

'All we ask for the old level playing field'

From page 17

advocating existing services, giving talks and publicity.

For example on folic acid, ASBAH had been involved in the production of one million leaflets to the public, health education agencies and professionals and had jointly organised a symposium which was well attended by national and international experts from medicine, biology, nutrition and industry, with representatives from two Government departments.

Spina Bifida Week, organised with the help of vitamin makers Larkhall Natural Health, was another successful vehicle in obtaining publicity for ASBAH - gaining coverage on 11 TV programmes and 52 radio stations nationwide and many magazines and newspapers.

Congratulations were extended to Tracey Proudlock on her video diary, Mother's Pride, which was screened on BBC 2 in the summer.

Civil rights politics

On the issue of civil rights for disabled people, Mr Russell stressed that ASBAH would continue to play its part, with other national disability groups, to keep up pressure on the Government.

He said: "The measures suggested by Government to replace rights have been discussed by our forum of members with disabilities, YVIA (Your Voice in ASBAH).

"They have recently come up with a very clear and helpful response which I believe should be a guide to ASBAH's policy on this important matter."

Mr Russell added: "What disabled people are asking for is the good old level playing field. Just like racial minorities and women, whose rights are now protected in law in important ways, disabled people suffer discrimination, and it is not enough to hope that society will gradually adjust attitudes, access and services."

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1994 AGM, NATIONAL ASBAH – FOUR-PAGE FEATURE

Tales from two hemispheres

TWO visitors from overseas, looking to take back information about ASBAH to their own countries, were special guests at the annual meeting.

■ WALLACE Sagansky is vice-president of the Spina Bifida Association of Canada which has been going for 14 years.

People with spina bifida and hydrocephalus are fortunate in Canada in that every city has specialised clinics, funded by the state, where clients can see several different specialists, he told *LINK*.

However, the association is run mainly by volunteers and is much smaller than its British counterpart. Canada has about 3,600 people directly affected by spina bifida and hydrocephalus.

Mr Sagansky's involvement in Canada's association stems from having a daughter born with spina bifida 19 years ago.

He said: "I didn't know anything about it and went to find out from a local group and got more and more involved."

At that time, there was no national organisation but a large number of local groups scattered across Canada.

Then - in 1980, the Year of Disabled People - the groups were given a grant to form a national organisation.

Mr Sagansky, an engineer working temporarily in Britain, is now keen to find out more about what goes on over here.

He said: "I'm impressed with the administrative set-up. You've been around for almost 30 years, whereas we are fairly young.

"We have common goals. We both have a folic acid programme to encourage women to take supplements.

"Our next step is to become involved internationally, depending on funding."



☆ Above: Mrs Sekatawa and her children in Uganda with (left) her husband, East African journalist Livingstone Sekatawa. Far left: Wallace Sagansky, vice-president of SBA Canada.

■ LIVINGSTONE Sekatawa has two daughters with hydrocephalus and the family had to travel from Uganda to Kenya in order for them to receive treatment.

Seven-year-old Sandra and three-year-old Sharon now both have hydrocephalus shunts fitted.

Mr Sekatawa is prepared to give up his job as journalist on the East African newspaper, *The Daily Nation*, in order to get ASBAH Uganda off the ground.

Mr Sekatawa said: "Ninety-five per cent of people with

hydrocephalus die very young.

"The new association will start small. I'm already in touch with some companies which are willing to lend a hand in helping to get an office which will act as a contact point."

The reason for Mr Sekatawa's visit to ASBAH's national centre in Peterborough was to obtain information before proceeding any further.

He said: "I hope to open the office for ASBAH incorporating Uganda in Kampala in October."

First executive elections for years!

FOR THE first time for as long as anyone can remember, there was an election to fill nine vacancies on the Executive Committee. Twelve people were nominated to fill these vacancies.

Those elected were: Geoff Baxter (Leeds and Bradford ASBAH, retiring member of executive), Edward Evans (Northern Ireland ASBAH), Brian Henley (retiring executive member), Charles Ortnor (hon treasurer), Eric Prentice (London NE ASBAH, retiring exec), Tracey Proudlock (YVIA), Zem Rodaway (YVIA, retiring exec), Alan Twyford (Surrey ASBAH, YVIA), Pauline Wood (N Wales ASBAH).

No mean result

SPENDING on services stayed the same in the year 1993/4 - no small achievement during a time of recession, according to honorary treasurer, Charles Ortner.

This had largely been achieved because the amount of money given to ASBAH increased during the year - a trend which could in itself mark the end of the recession.

Mr Ortner said the total operating deficit for 1993/4 (£69,857) shrunk to just £11,000 when the cost of setting up of ASBAH's new trading company, Computer Sense Ltd, (£58,487) was deducted.

This compared extremely well with the operating deficit of the previous year which stood at £76,976.

Guarantee on non-duplication

ASBAH national centre came under fire from a local association representative who claimed too much was being spent on salaries.

Geoff Harrison, treasurer of South Thames ASBAH, was referring to the £1,246,916 spent on staff wages and salaries, as revealed in the *Annual Report and Review 1994*.

The organisation, he said, was becoming too top-heavy and there was the danger that regionalisation would simply duplicate services.

Mr Harrison said: "You are keen on regionalisation but are bound to keep staff at head office here.

"What we want is fieldworkers not administered locally. Decentralisation is a national trend which ASBAH is blindly following. For ASBAH, it's going to be expensive at a time when we can't afford it.

Any extra should go into providing services."

His comments were answered by ASBAH's executive director Andrew Russell and chairman Patrick Daunt.

Mr Russell said expenditure had, in fact, gone down and the number of staff employed had fallen.

"The way money is spent is always under review. The general philosophy of ASBAH is as a provider of services and services expenditure."

Chairman Patrick Daunt commented: "We are keeping a constant eye on avoiding duplication of effort and I give my guarantee that the points you've raised will be looked at. Our next strategy planning meeting of the executive committee is due in the spring."

'Three projects ready when funding allows'

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Mr Russell said it had been a year of great demands on ASBAH staff and services, as had been shown from fieldwork reports and regional reports. Yet the organisation had been unable to develop services significantly because income had broadly stayed the same as in the previous year, while costs had risen.

He said ASBAH had continued to make strong bids to local authorities for fieldworker services and there was scope for contracts once the new system of Community Care planning has settled down.

He reported on plans to launch two new regions - the Eastern Region and Northern Region.

These would add to the Northern Ireland Region and SE Region, which had showed success in creating better networks for onward referral as well as bringing information and training about spina bifida and hydrocephalus to fellow professionals.

Mr Russell said START - our new Service Team for Assessment, Rehabilitation and Training - would pick up from where Five Oaks stopped, after providing a service for 18 years.

The setting up of a new Education Advisory Committee was mentioned, together with the appointment of education adviser Peter Walker as a member of the new Special Educational Needs Tribunal.

Two projects funded through ASBAH's Medical Advisory Committee - one into drug treatment for hydrocephalus and the other into lack of knowledge about folic acid among women of child-bearing age - are currently underway. Mr Russell said: "Shortage of funds has limited the amount of new research we can initiate at present, and we have at least three projects ready for funding when circumstances permit."

With ASBAH's support, a national hydrocephalus shunt registry had been funded by the NHS, together with an evaluation unit which tests shunts in laboratory conditions at Addenbrooke's Hospital in Cambridge.

Mr Russell said: "These developments are overdue, in the sense that factual information about the performance of shunts, and a central database of people with shunts, will add to the safety and effectiveness of shunts nationally."

Listen to our needs!

Particular thanks are extended to the following all the young people and families, the residential units I visited during the study, ASBAH's fieldwork department (in particular Gina Broughton, Teresa Cole and all fieldworkers), Dr Dot Lawton at the Family Fund, York, Mr Chris Rassdale and finally Doctors Martin Bax, Hutchins and O'Donahue, who carried out the medical assessments.

AN INCREASING number of reports are now being written by carers for carers (Cowen, 1994) or by researchers with disabilities, who address the specific needs of disabled people (Oliver, 1992; Reiser, 1993). This article describes the personal views, concerns and needs of 95 young disabled people, aged between 16 and 25, who have spina bifida and/or hydrocephalus.

Although undertaken by an able-bodied researcher, advice about questionnaire/interview design was obtained from a young person with spina bifida. He was not part of the research sample. His contribution was pivotal to the development of this research and is much appreciated.

STUDY AIMS

To examine the educational, career, work and housing opportunities available to young people and to establish to what extent these are met.

To review and evaluate the provision of health and social services both prior to and post-leaving school.

To review the current medical health status, in particular shunt/catheter care, urinary incontinence and the young person's or carer's ability to deal with these.

In the last of a four-part series for LINK, our former research fellow **MADDIE BLACKBURN**



reports on the findings of her study into the health and social needs of young adults with spina bifida and/or hydrocephalus. In particular, she discusses their health status, independence training, career opportunities, access and mobility.

To assess the degree to which young people with spina bifida achieve independence in adult life and examine the possibilities and opportunities offered to them for living independently.

To provide some baseline information about the young person's health, educational and social development.

To examine the opportunities offered to young adults to make relationships with their peers.

METHODOLOGY

The study was carried out in the North West Thames region. All the young people were known to the former Westminster Children's Hospital. Some of the people interviewed now live in Kent or Surrey. Others were contacted through the Family Fund, Social Policy Research Unit, York, ASBAH's fieldwork database, the Westminster Hospital medical records department, district and local social service departments registers. Approval for this study was obtained from the local research medical ethics committee.

Over the last two decades there has been an enormous decline in global spina bifida births. In the 1970s birth prevalence was about 4.5 per 1,000. In 1991 it was only 0.18 per 1,000 in the United Kingdom (Seller, 1994). Birth prevalence within the North West

has traditionally been higher than in the South East of England (OPCS, 1993).

At the beginning of this study the population within the North West Thames was thought to be about 618,874 with a low prevalence of spina bifida. Originally we anticipated contacting about 200 adults with spina bifida. We only identified 164 people. Of these, 50 young people were contacted by the Family Fund. Only 18 replied. Of the 18, four people had died, seven had moved away from the region or were no longer in touch with the former Westminster Hospital. Two young people were geographically out of scope for this study. From our other sources, 18 people refused, 23 had moved and no contact address was available and a further 12 had died. Ninety-eight adults agreed to take part but three were geographically out of scope.

It would seem that the original, identified sample size was probably representative of the overall number of people with spina bifida and/or hydrocephalus living within this region.

Information was obtained from 95 young adults between ages 16-25 years. 16-19-year-olds were also included in order to determine the needs, expectations and concerns both before and on leaving the

Continued on page 22

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school system. The majority of respondents, however, were over 18 years at the time of interview.

All young adults were sent an explanatory letter outlining the aims of the study (*listed above*) and inviting their participation in a personal interview. The interviews took place either at home, hospital or other mutually convenient venue. A separate letter and consent form was sent for the medical component of this study. Where necessary or requested, a preliminary home visit was offered to provide further information about all sections of the study. Three young people asked for this prior to the first interview. Many parents opened and answered their son or daughter's correspondence on their behalf. Several parents telephoned for further information.

Information was obtained through two separate interviews, mainly undertaken by the author. Dr Martin Bax or his senior registrar carried out a separate health assessment either within home, hospital or residential institution. Maddie Blackburn attended most of the medical assessments and all those involving women.

During the social health interview with the young person, carers were invited to complete a separate questionnaire either independently or with the help of the researcher. This section of the study was described in the last edition of *LINK*. The carer interview aimed to offer reliable back-up to the information provided by the young person (particularly for those people in the study who had associated retentive memory difficulties). Several young adults asked their carers to be present at the interview. Some parents asked to attend and others insisted on being present.

Ninety five young people took part in the medical interview but only 44 agreed to medical

examination. The medical assessment was divided into two sections, an interview and an examination. Most of the medical assessments were carried out at home or in residential units with the prior permission of the authority concerned. We think the home-based assessment may have influenced the higher refusal rate for the medical examination. A hospital-based assessment was also offered but travelling and inconvenience meant this was not always feasible for the young person. Clearly the demand for long-term adult medical assessment is indicated by the increasing number of new referrals which the young adult disability service at Chelsea and Westminster Hospital, London continues to receive (reported in a recent edition of *LINK*).

The medical interview included questions about childhood surgery, specific health problems, hospital and general practitioner support. The second section included measurements of blood pressure, head circumference, arm span and examination of the spine and valve. Carers and hospital medical records provided valuable information and accuracy about investigations, number of operations and dates.

A semi-structured client-led interview was carried out on a random selection of 20 young adults living at home, independently or within a residential setting. The flexibility of this approach in some cases succeeded in elucidating the young person's opinion on more sensitive matters particularly sexuality.

SOME RESULTS

EDUCATION AND EMPLOYMENT

The majority of young people at some point of their school life had been educated within a special school. Those who started in special schools found it difficult to change to mainstream education

later on. A higher proportion of under 20-year-olds had been entirely educated within mainstream schools. Many of these had only achieved this by sheer self-determination or parental pressure. Most young people would have preferred to have attended mainstream schools because they felt their curriculum and employment opportunities would have been greater. However, those who argued in favour of mainstream education were less positive about access and facilities in such schools, such as toilets, stairs and adaptations. Many welcomed the idea of the specialist unit within the mainstream school, regarding total integration as an unrealistic goal. Some had studied at a college of education after leaving school. Most had received a broad curriculum, with many undertaking computer training and vocational courses but only a minority had sat GCSE (or their equivalent), A-levels or were contemplating going to university. Many felt that they needed more reading and writing skills.

Clearly this was an area where many young people reported enormous problems. Those who entered employment training or found a job in open or sheltered employment were frequently the least disabled among the sample. The more complex the disability, the greater the difficulty they had in gaining employment, particularly those with complications frequently associated with hydro-cephalus. One young man, with the help of an independent grant, was studying for a doctorate. He had completed his first degree. His experiences were unique. For most people, after they were 21, there were limited training and employment opportunities - with many returning to full or part-time care of parents at home.

ACCESS AND TRANSPORT

Access to buildings or strict fire regulations often compounded

their difficulties in employment or further education. Five young people had developed sign language interpretation skills at school. Two had been accepted on to advanced training programmes. Inadequate building access and poor transport obliged them to reject such places.

RailTrack's and London Transport's attempts at improving access facilities for the disabled traveller clearly do not go far enough. The few who used such methods of transport frequently planned their excursions weeks in advance. Eight people reported spending their undignified rail journey in a guard's van, this being the only place to accommodate both the young person and their wheelchair.

However, some young people were clearly undeterred by travel difficulties. Air travel was surprisingly particularly popular. A certain airline company, renowned for its care and attention for people with disabilities, had been used by eight people. The company often provided additional staff, where indicated, and suitable access for wheelchair passengers.

INDEPENDENCE

Many attended independence training programmes at Five Oaks, Banstead Place, Stroud Park, Dorrin Court and Chailey Heritage but several reported long waiting lists to obtain places and funding. Twenty referrals were made to ASBAH regarding independence training during the course of the research. The recent closure of Five Oaks will undoubtedly leave an enormous gap in independence training opportunities.

The majority of the sample were regular wheelchair users. Only 10 of the sample walked independently or mainly used crutches. Many young people who had previously used calipers or sticks had stopped using them between 12 and 15 years of age; the ease of the wheelchair, associated weight problems compounded with

frequent orthopaedic surgery being cited as reasons for discontinued use.

SOCIAL LIFE AND FRIENDSHIPS

Although the young people felt that they had opportunities to form and have relationships with their peers only 42% said they had either visited or 38.7% said they had been visited by a friend during the last week (see Tables).

MEDICAL CARE

Generally people were happy with healthcare service provision until they left school. Most of our sample were happy with health care provision after 18 years of age because they were regularly attending an adult specialist

service. However, views of people in the North West Thames region are probably unrepresentative of those young adults with spina bifida living elsewhere in the United Kingdom. Many young adults with spina bifida/hydrocephalus as yet do not have access to an adult, multi-disciplinary specialist service.

Many young adults had undergone in excess of 20 operations; mainly for neurological, orthopaedic and urology procedures. Pressure sores on the feet, back and buttocks frequently required surgical debridement or prolonged treatment. Urinary tract and catheter infections, particularly in males, were also noteworthy. Back, mobility and urinary problems were of notable concerns (see Table 6).

TABLE 1

STUDY	Nos
Young adult interviews	95
Parent interviews	65
Young adult medical interviews	95
Medical examinations	44

Total young adults N = 105.
Total parents = 80.

TABLE 2

Young Adults - When did a friend last visit you?		
Time	N =	%
Within last week	36	38.7
Within a month	19	20.4
Within 3/12	6	6.5
Within 1 year	13	14.0
Never	18	19.4
Not answered	1	1.1

Total = 93

TABLE 3

Young adults - When did you a friend last visit?		
Time	N =	%
Within last week	39	41.9
Within a month	19	20.4
Within 3/12	8	8.6

Within 1 year	13	14.0
Never	12	12.9
Not answered	2	2.2

Total = 93.

TABLE 4

Medical examination - Abnormality of lesion

	N=	%
Deep pitted	7	15.9
Kyphosis	7	15.9
Keloid scars	6	13.6
Pad of hair	5	11.4
Abnormal	21	47.7

Total = 44.

TABLE 5

Young adults - When did you last go to a party?

Time	N=	%
Within last week	9	9.7
Within a month	19	20.4
Within 3/12	19	20.4
Within 1 year	21	22.6
Never	25	26.9

Total = 93.

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TABLE 6

Young adults - Particular worries.

86% Urinary incontinence

67% Bowel problems

42% Performing manual evacuation

32% Using clean intermittent catheterisation

83% Particular mobility problems

79% Mobility aids

67% Skin problems

40% Particular sexual problems or other anxieties.

N = 95.

TABLE 7

Parent/Carers

48 mothers/females

17 fathers.

TABLE 8

Parents - Do you still assist with urine management?

YES	NO	NOT ANSWERED
n 19	20	24

Total = 63.

TABLE 9

Parents - Do you still assist with bowel management?

Yes	No	Not answered
n 15	23	25

Total = 63.

TABLE 10

Parents/Carers - Satisfaction with mobility and access.

COMMENT	YES	%
Poor	3	4.8
Fair	11	17.5
Good	15	23.8
V Good	19	30.3
Excellent	7	11.1

CONCLUSION

This detailed study has implications for both statutory agencies and legislation. It has been agreed that a detailed appraisal of some of the recommendations and additional findings will be discussed in a future edition of *LINK*.

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MADDIE BLACKBURN is project research development officer for the Queen's Nursing Institute in London. She is also honorary research health visitor at Charing Cross and Westminster Medical School.

PENNIES from heaven showered upon ASBAH after a man jumped out of an aeroplane on his 62nd birthday.

Ron Brine, from Whittlesey, near Peterborough, jumped in tandem - strapped to an instructor - and fell 12,000 feet to raise more than £700.

Ron was one of almost 200 people who took part in a national sponsored parachute jump from centres up and down the country in September.

They were taking part in a national sponsored parachute jump held to raise money for ASBAH and The Children's Society - with almost £14,000 counted in so far, and the last payment-stragglers being chased up at the moment. The proceeds will be split between the two charities. One of the busiest jump sites was in Sussex where 40 volunteers had been roped into the event by Sussex ASBAH.

Mr Brine, pictured with his cheque and Elissa Lowder from ASBAH's appeals department, did his jump at Sibson Airfield, near Peterborough, with 12 others - the rest opting for a full weekend's training before doing their 'static line' jumps from 2,000 feet.



Ron showers pennies from heaven!

HOW WELCOME to hear Dr Pat Tomlinson, recently retired school doctor at Lord Mayor Treloar College in Hampshire, talking about shunt problems in adults at our recent staff training course.

Dr Tomlinson, who contributed to our shunt leaflet being sent out to GPs around Britain, probably had the country's biggest list of young patients with spina bifida and hydrocephalus while in general practice at Treloar for 16 years.

Our fieldworkers and disabled living advisers have between them an even bigger list of clients. It was good to hear the exchanges and find a doctor who says that it is essential with hydrocephalus shunts to place faith in non-medical opinion - the other carers in the professional team, the close family - to pick up early warning signs of when things go wrong.

YOU THINK *we've got problems with the health service in the UK? They are not a patch on those faced by one visitor to our recent annual general meeting.*

Livingstone Sekatawa, who is planning to set up a version of ASBAH in Uganda, travelled to Britain to spend a week picking our brains on how to go about it. And his personal story showed just what an uphill struggle is in front of him.

Mr Sekatawa and his wife Robinah have two young children who have hydrocephalus who must travel to neighbouring Kenya for their shunt operations. He is fortunate in being able to travel as a correspondent for East Africa's biggest newspaper, the Nairobi-based 'Daily Nation', because the mortality rate for children with hydrocephalus in Uganda is apparently 95%.

Mr Sekatawa was staggered to meet adult survivors with hydrocephalus while in the UK - many doing well and living full and active lives.

BALLOON races are big business, with thousands of prize claims

The LINK diary

This and That!

being returned to ASBAH each year as finders try to help entrants win champagne or a watch for the longest distances travelled. But the return of one such weather-beaten docket, accompanied by a letter in meticulous copperplate, stood out from the rest.

The balloon had been found near Gravesend in the garden of cult film director Derek Jarman, whose prolific output includes the critically-acclaimed 1991 movie *Edward II*. The letter-writer thought we might be interested in the celebrity owner of this English country garden.

Strange the fate of things inanimate: a touch more wind and the balloon might have travelled a bit further, perhaps touching down in the North Sea. And the chance to write this quirky item would then have been lost for ever.

TALKING *of twists of fate, let's hope that Rob Barsby, the intrepid windsurfer who attempts to set up a record next Easter for the fastest time to sail two ways across the Wash, does not come across the difficulties encountered by another board-sailor in 1986.*

I have just received a cutting from a kind of 'Down Memory Lane' book which recalls how Mr Jeffrey Gill decided to raise £1,000 for the Bude coastguards by windsurfing from the North Devon coast to Lundy Island. When, several hours later, there was no sign of him, the coastguards launched a full-scale air-sea rescue operation involving the Bristol Channel lifeboat, the Lundy ferry, the Bude inflatable life-raft, a helicopter from RAF Chivenor and mobile coastguard units from as far away as

Cornwall. The total cost of the operation was £2,000 - exactly twice what he had hoped to raise.

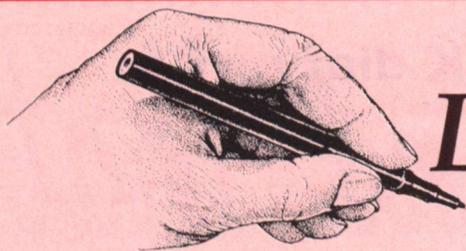
Eventually, Mr Gill was found - the wind out of his sail and floating with the current towards America. "The wind dropped and my flares didn't work", he explained sheepishly.

No chance that the charities being backed by Rob Barsby will ever allow him to become similarly becalmed. He will be raising money for ASBAH and the Royal National Lifeboat Institution! And there should be a small flotilla of craft following him, just to make sure.

ARE WE on to a winner yet with the National Lottery, which started last month? Not a bit of it! The lottery, busy creating a millionaire every week, has failed to get its act together in two key areas: (1) it has set up the board to allocate money to charities but the board will not be ready to distribute funds until the end of next year and (2) a lot of money given to good causes will go to the arts, which are at the bottom of most people's lists of things which they want to support. Dip into your pockets for us please, we still need you!

WE REALLY *have got it made in another area! Or does someone out there need their head examining? An American company has sent an entry form to a former LINK editor for inclusion in next year's Marquis Who's Who in the World, described as 'The Definitive International Register of Outstanding People'. In the self-deprecatory style of the true Brit, we could not take these particular Americans seriously. So yet another mailing shot was consigned to the WPB.*

B



Letters



To Paul Darke, *LINK*
film writer:

I ENJOYED Paul Darke's article, *Disability on Film*, very much. It was interesting, well-balanced and well-written.

However, conspicuous by its absence is any mention of one made-for-television documentary about a person with spina bifida - *Let's Take That Infernal Risk*, featuring ASBAH's president Dr Jeffrey Tate.

If you have not seen the film, I hope you will have the opportunity to do so. It was produced by Patricia and John Ingram for Central Television and telecast on Channel 4 on 4 January 1987.

The people at Central Television graciously allowed me to view it while I was researching my Master's thesis - a biography of Dr Tate.

Also, I would be very interested in reading your dissertation when it is completed. Will it be available through a dissertation indexing service?

Madeline Jenkins Millard
E Buena Ventura Street
Colorado Springs, USA.



To Paul Darke, *LINK*
film writer:

I WAS interested to read your film column in *LINK*, and take your point that there seem to be no major films featuring people who have spina bifida and/or hydrocephalus.

But I must tell you about a film that we have recorded and watched several times with great enjoyment.

My daughter Carys (now aged 13) has spina bifida and hydrocephalus and uses a wheelchair, so we were delighted to find a film entitled *Mac and Me* which stars a boy in a wheelchair, who seems to have spina bifida although the disability is not referred to, except that the home is

"wheelchair-friendly" and he displays great independence.

It is a Vision International Film, directed by Steward Raffil, an RJ Louis Production.

The wheelchair-bound boy Eric is played by a young actor called Jade Caleygo, but I feel sure his disability is genuine.

The film is an "ET" type story and is very entertaining for children. I particularly like the way the disability is not made an issue of and there is no sentiment or self-pity.

I hope your column in *LINK* is to be a regular feature. I am glad to see the magazine is broadening its horizons.

Caroline Nicholas,
Cardigan, Dyfed, Wales



Your letters are invited for publication. Please send them to Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ. The Editor reserves the right to edit them for publication, so please keep them as short as possible.

1995 DIARY DATES

Thursday, 19 January

Managing Innovation, a BT Charity Talk Speakers: Elisabeth Hoodless (executive director, CSV), Dr Liz Nelson (chief executive, Princess Royal Trust for Carers). Cavendish Conference Centre, Duchess Mews, London W1, 5.45 for 6.15pm. *Ticket only, apply Mary Harris, tel 0171-477 8667.*

25 - 26 January

NCVO annual conference and AGM, London. Speakers include shadow health secretary David Blunkett and home secretary Michael Howard. *Vivienne Robb,*

NCVO, tel 0171-713 6161.

20 - 24 February

ASBAH residential course. 'Looking at Myself', in association with Surrey Phab, Felbury House, Holmbury St Mary, Dorking, Surrey. A total of 15 places will be offered to young people aged between 12 and 18. *Details: Caroline Berkley, ASBAH, 123 East Barnet Road, New Barnet, Herts EN4 8RF, tel 0181-449 0475.*

24 - 26 February

ASBAH Parenthood course, 'Parents with disabilities and their families', Hereward College, Coventry. *Details: Joan Pheasant, START manager, tel 01943-609468.*

7 - 9 April

ASBAH South East Region 'Music and Drama Weekend' for young people aged 10 to 16, Meldreth Manor, Royston, Herts. Funded by BBC Children in Need Appeal. *Details: Gina Broughton, ASBAH S E Region, 123 East Barnet Road, New Barnet, Herts, tel 0181-449 0475.*

Easter Bank Holiday weekend

Olympic hopeful Rob Barsby attempts *The Wash Windsurf Challenge* in aid of ASBAH and RNLI. *Details: Deirdre Pawsey, Fundraising Department, ASBAH, tel 01733-555988.*

FOR SALE

NISSAN Vanette Versa Plus conversion. Removable passenger seats. Takes one wheelchair and five passengers or two wheelchairs and three passengers. Ramps fitted and electric winch. One year old. Tel: 01253-761283.

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

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ISLE OF WIGHT ASBAH

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Small adverts for the next issue of LINK (February) should be submitted by Friday, 13 January. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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