

Link

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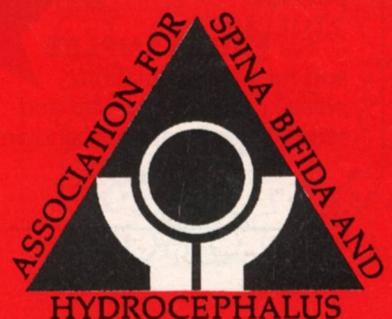
The magazine for people with
Spina Bifida and/or Hydrocephalus



IN THIS ISSUE

Tourism for All awards

Fieldwork - the men's story



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BEFORE the last of the turkey has been eaten this Christmas the holiday companies will start to woo us, hoping we'll spend our summer holiday as their paying guests. Advertisements for locations from Britain to the Bahamas will appear on our screens, in newspapers and magazines, in an effort to make the viewer 'wish you were here'.

Of course, for everyone there are restrictions as to what kind of holiday we can have because of financial and time limitations but for disabled people there's another hurdle - practical problems of getting to the destination, finding suitable accommodation and, once there, will the 'tourist attractions' be accessible?

With these thoughts in mind, in this issue we have two articles on transport, and the progress which has been made in making it easier for those with special needs to get from A to B. And there's good news for those wishing to take a holiday in Britain with the announcement of the Tourism for All awards - Tony Britton looks at the facilities offered by the winners and gives a list of accommodation throughout the country which fulfil the criteria for the new 'accessible' symbol.

For a holiday with a difference, consider the 1991 IFHSB Congress in Sweden - a chance to meet other families, find out more about many aspects of living with spina bifida and/or hydrocephalus and have a holiday abroad in the beautiful Swedish Archipelago - more details can be found in our 'Out and About' section.

1991 - a very special year for ASBAH

Next year is a special one for ASBAH - our 25 year anniversary. Plans are under way to celebrate this event and a date has already been fixed for an oecumenical service of rededication at Peterborough Cathedral for 13 July, followed by a garden party. Details of how to apply for tickets will be announced later.



COVER - Sean Walsh meets the Princess of Wales after his performance at Sadlers Wells - full story on page four.





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Mr Roy Johnston

Liver and Vitamin A

The Department of Health has recently recommended that pregnant women should not eat liver. The committee on toxicity which reports to the Department advises that eating liver exposes pregnant women to levels of vitamin A that might endanger the health of the baby

Liver has always been recommended to pregnant women in the past, but the current practice of adding the vitamin to animal foodstuffs has led to potentially dangerous concentrated levels in liver. Although the evidence linking liver consumption to birth defects in the UK is weak, women who are taking Pregnavite Forte F are already supplementing their diet with vitamins and, therefore these women are particularly recommended not to eat liver.



Star of stage and screen

FEATURED on our cover this month is 11-year-old *Sean Walsh* from London. Sean's acting and singing abilities meant he had a major part when the Chicken Shed Theatre Company staged 'Anansi' at the Sadlers Wells Theatre this autumn. The Princess of Wales was guest of honour at the performance and met Sean backstage when he presented her with the company's T-shirts and badges for princes William and Harry.

It was the princess's suggestion that they contact Blue Peter and Sean has since appeared on that programme.

Sean attends a mainstream secondary school, which he started this year. He enjoys basketball and swimming but the theatre group is "what he likes best". He's been going to the group for over three years since his aunt suggested it. Chicken Shed meets on Thursday evenings and there are disabled and able bodied children in the company of some 300 members. There is a waiting list to join the theatre group. For more information about Chicken Shed ring 081 882 6345.

Fresh start for Stockport

At a extraordinary general meeting of the Stockport association in August there was just one item on the agenda - a proposal to dissolve the Stockport and Tameside Association for Spina Bifida and Hydrocephalus. The days of this local association appeared to be numbered following a gradual decline in its activities over several years. But the association got a reprieve when an amendment was made to the solitary proposal - that they would dissolve the association on 27 October unless a new committee could be formed by that date.

Parents in the area, who had been meeting informally at coffee mornings in their own homes, decided they would take up the

challenge of organising a formal association and at the meeting in October a new committee was elected and the Stockport and Tameside association is once again in business.

The committee hopes to keep families and individuals in touch with one another and the informal coffee mornings will continue. Fundraising and social events will be organised and they also intend to liaise with national ASBAH to collect and make available information on education, medical and social matters. Locally they aim to improve services in their area. We wish them well in their new venture.

Their new secretary, Janice Roberts, can be contacted on 061 430 4867.

Huge interest in top post

Interest in who will succeed Moyna Gilbertson as ASBAH'S executive director peaks this month. An announcement on a successor is expected shortly after interviews are held in Peterborough on 12 December.

A total of 448 inquiries were received after the position was advertised nationally in October and November, and 169 of these converted to applications by the closing date. Miss Gilbertson, who has been the association's chief executive for over 14 years, will retire in April.

Congress disappointment

The Congress of the European Union of Associations for Spina Bifida and Hydrocephalus - held in Greece earlier this year - was attended by our fieldwork manager, Teresa Cole. Unfortunately it did not live up to expectations...

The congress coincided with a general strike in Greece causing all kinds of problems for the organisers as power cuts threatened to interrupt meetings, and public transport and most other services were out of action.

The day of the conference itself bore little resemblance to the promised programme; with no attendance by ministers, no workshops or discussions and fewer participants than expected.



Maria in her daily environment.

However, delegates did manage to see some of the establishments in which children and adults with spina bifida were living and reported that many improvements were needed. Teresa was particularly moved by the plight of one intelligent teenager, Maria, with spina bifida who seemed to be in "totally inappropriate accommodation" - a unit for all ages from babies to young adults, including those with severe mental disabilities. The teenager received only one hour's tuition a day because, the delegates were told, she could not get her wheelchair into any school nearby.

Despite the difficulties Teresa hopes the conference did go some way to arouse the interest of the country's professionals in the need for improved support for people with spina bifida.

Appeals Changes

At a meeting of the Executive Committee held on 12 October 1990, a decision was taken to restructure ASBAH's Appeals department. As a consequence, two posts were made redundant, including that of the appeals director.

The department is now being managed by Roy Johnston, who joined ASBAH earlier this year as our direct mail specialist. With Derek Knightsbridge, Finance Director, he is now concentrating on two main areas of work - a business sponsorship campaign

and enhancement of our appeals through direct mailing.

Penny Hebblewhite becomes the appeals department's main contact person for local associations. If they require help with their own fund-raising and appeals, or any related questions, they should contact her.

ASBAH no longer runs events on its own behalf as the majority of such events do not result in enough revenue coming into the association to justify them. The appeals department, however, will continue to co-operate with any organisation or individual planning to raise money for ASBAH and will willingly work with them where there are obvious, mutual benefits.

OBITUARY

Mrs Dorothy Artingstall

The chairman of Midland ASBAH, osteopath Mrs Dorothy Artingstall, died in hospital in November, aged 70.

Our West Midlands field worker, Lettie Bellshaw, recalls her boundless energy and enthusiasm.

"In 1973 Dorothy was invited to become chairman of MASBAH, a task she immersed herself in from the beginning with tremendous enthusiasm, a boundless energy and drive which often left those around her breathless. Her commitment to the individual with spina bifida or hydrocephalus and to the policy and aims of the association was undoubtedly wholehearted. An advocate and ambassador on behalf of the association she tackled those in authority, in health, social services, housing and employment, in an endeavour to secure better provision and resources for those she sought to serve.

Dorothy possessed the gift of capturing the imagination and confidence of those she led to the extent of carrying them with her into projects that by rational standards would seem unattainable. She convinced committee members, volunteers, staff and friends that success was possible.

A tireless, imaginative fund raiser she organised jumble sales, Christmas fairs, carnivals - to mention a few - all with the aim and vision to help and improve the quality of life for those with spina bifida and hydrocephalus.

She believed and worked for the fundamental dignity of individuals and strived in all her efforts to that end.

In 1988 she won a Whitbread Community Care award for outstanding voluntary service to the community, having been nominated by ASBAH's executive director, Moyna Gilbertson.

We pay tribute to Dorothy Artingstall's service for MASBAH and the spina bifida and hydrocephalus sheltered workshop and know that her influence will live on in the projects she started and the lives she affected and we give thanks for her commitment and dedication."

Mum's a winner

Life for 22-year old Jane Baker from Southampton, who has spina bifida, should be a lot easier following her mother's win of over £16,000 at Leisure Bingo in Woolston.

Mother, Carol, was one of four winners in the national game which is played nightly in more than 600 bingo clubs around the country. Her winning total of £16,265.46 will go towards an extension at the family home, including a downstairs bedroom and shower room. "I know the money will help to make Jane's life a lot easier," said Mrs Baker. Work on the extension will start in the new year.



Mrs Baker receives her winner's cheque, with the manager and deputy manager of the Leisure Bingo club.

Evaluating Perinatal Care

A major new initiative has been launched by the Perinatal Trials Service to carry out rigorous tests on whether the 'treatments' offered to women in pregnancy, childbirth and the early postnatal period, and to their newborn babies, are really effective.

"Surprisingly, the benefits and hazards of many procedures and practices in maternal and newborn care are not known," said Dr Adrian Grant, Director of the PTS, "It needs very large, multicentre trials to assess reliably how useful or harmful particular forms of care are. Failure to mount such trials in the past has hampered the introduction of useful treatments, and prolonged some ineffective practices."

The school of her choice

Earlier this year we carried the story of Dorothy Dearing's personal fight to get her daughter Kristen into the local High School, with her friends from middle school, rather than being sent to a designated school seven miles away. After keeping Kristen off school for 18 months, while they fought it out with the authorities, she was finally allowed to go to the school of her choice in January.

Almost a year has passed and we are able to report that Kristen is very happy at her local school, Cramlington High, in Northumberland. Adaptions to the school, for Kristen, include toilet facilities, lowered benches, sink unit and hob in the domestic science room and ramps in various parts of the school. The school also has a Mobility 2000 wheelchair for her use. Kristen goes to and from school on her own and "is doing well" says her mother, who is glad things have turned out as they hoped and made all their efforts to get Kristen accepted worthwhile.



Guest of honour

When the former secretary of Surrey ASBAH got married there was a special guest at the wedding. Trudy-Anne Bush, who has spina bifida and hydrocephalus, was attended by her god daughter, two nieces, her nephew... and her cat. Trudy wanted her special pet, who has only three legs, to be part of the celebrations when she married Richard Eborn this summer and, of course, it turned out to be a purrfect day!

Trudy-Anne and Richard with their special guest.

Riding with Rudolph



Whilst the rest of us must wait until 24 December for Santa's sleigh to visit, Helen Wall, daughter of Suffolk ASBAH's secretary, will be able to ride in it five days before Christmas.

Helen, aged 9, has spina bifida and was nominated for the trip to Santa's home town, near the Arctic Circle, when her local chemist shop won a Seven Seas competition for its window display. Part of the prize was a day trip, for one of the chemist's customers, to see Santa.

Helen and her parents fly north at 7.40 am on 20 December to visit Santa Claus village, do some Christmas shopping and then take a "Trip into the Wilderness" for an Arctic Circle crossing ceremony. Then they can take their sleigh ride with Santa's reindeers. In the evening there is a Christmas feast and a present from Santa before they leave for the three hour flight home.

Breaking the record



A 16-YEAR OLD schoolgirl with spina bifida is the youngest car driver in Britain and her name will be in the Guinness book of records to prove it. Melody Hunter, from Walsall, became Britain's youngest driver when she passed her test at the age of 16 years and 53 days.

The fact that those in receipt of mobility allowance are allowed to take their test up to one year earlier than able bodied motorists is not always realised - Melody's dad, who is a manager with the British School of Motoring, even had to argue the point with the driving test centre when he put her in for her test.

Although he's a qualified instructor Melody's dad didn't teach her to drive - neither of them thought this would be a good idea - but Melody had lessons from two of the instructors at BSM.

Melody drives an automatic Austin Metro with hand controls.

Her mum says Melody was delighted when she passed her test and they "haven't seen her since!" - not only has it given her more freedom and independence but she's the envy of all her able bodied friends who will have to wait until they reach 17 before they can drive a car.

Winning personality

Suzanne Evans' time and effort on behalf of her Phab club was rewarded when she was named Personality of the Year in the youth category of the midlands Phab awards. Twenty-three year-old Suzanne, who has spina bifida, has been a popular member of the Lyndon Senior Club in Solihull since she joined, 15 months ago. She is on the area committee for the West Midlands and helps organise fund raising. She has also represented her club at Phab's national conference.

"Suzanne has given lots of time and ideas to the club and in return she has received confidence to help her in her everyday life" said Phab. And next year will bring a new experience for Suzanne when she goes on holiday, with the club, to Stackpole - the holiday adventure centre in Wales - where she can try horseriding, rock climbing and abseiling.



Number please

British Telecom are to start charging for calls to directory enquiries from April next year. But there will be a free enquiries service for people who have a "medical condition or physical disability which prevents them from using the printed 'phone book".

Hydrocephalus is one of the qualifying conditions for the free service - to obtain an application form telephone 0800 800 804

'A lead for the travel industry

Adventure park sets the pace

HOLIDAY centres which give disabled visitors the freedom to explore just like anyone else have been boosted by their very first national competition.

Experts seeking the United Kingdom's best facilities for all visitors have awarded the first prize to a family adventure park in Cornwall - in the first-ever national contest when the needs of people with disabilities ranked equally with everyone else.

Dobwalls Family Adventure Park, near Liskeard, came first for its efforts to ensure that all visitors receive equal standards of service and care in the 'Tourism for All' awards for 1990.

The adventure park, run by the same family for 21 years, will now represent the UK in the European finals to be played off in March.

Dobwalls, owned by John Southern and his family, faced stiff opposition from the Jane Hodge Hotel in Wales, the Mill Croft Guest House in Scotland and Erincurrah Cruising, Northern Ireland.

Judges, including Holiday Care Service director Maundy Todd, voted first place for Dobwalls as "the most complete example of the philosophy of 'Tourism for All' in practice and in action".

Disabled people visiting Dobwalls can take part in all the activities enjoyed by able-bodied people. These include the Forest Park miniature railway, Adventureland and its Thorburn Gallery complex, featuring a Victorian tea room and Edwardian penny arcade.

William Davis, chairman of the British Tourist Authority which co-ordinated the UK competition, said: "Most of us take for granted the ability to enjoy travel and tourism".

"The Tourism for All campaign aims to make these pleasures as widely available as possible, and Dobwalls does just that - in a positive, unsentimental and fun way. They're giving a lead for others in the industry to follow."

The European winner of the competition will be announced next year at an international 'Tourism for All in Europe' conference to be hosted by the English Tourist Board and the Holiday Care Service. This will be held at the new Gatwick Sterling Hotel next March.

In July, the Holiday Care Service

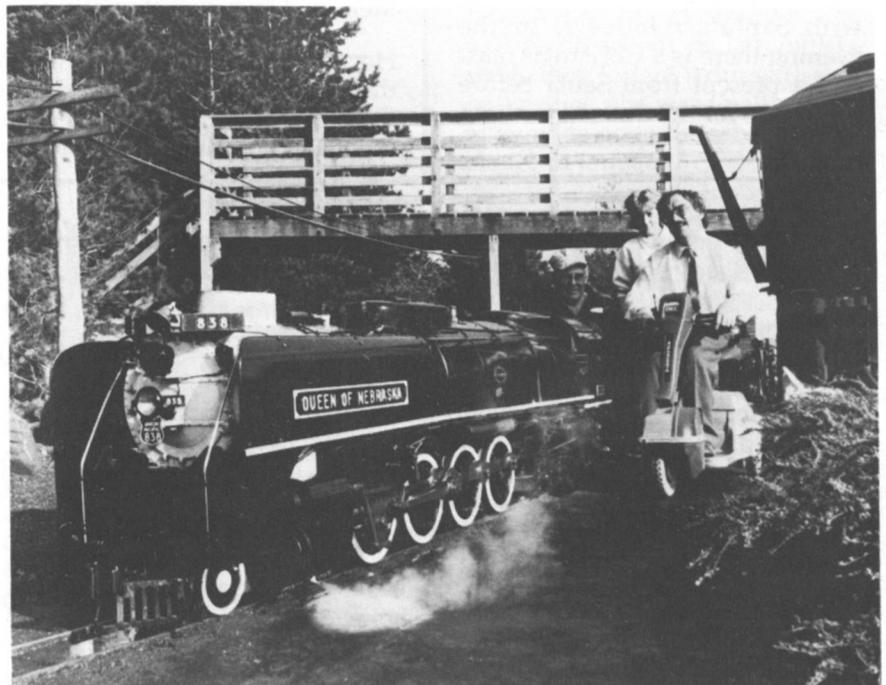
launched its own Tourism for All 'Accessible' symbol - awarded only when establishments have been inspected and verified as fully accessible to disabled guests. So far, 40 places have won the coveted symbol, including 26 major motor-route units in the Travelodge chain.

Railroad attraction on the right track

Dobwalls, west of Liskeard on the main railway line, started life in May 1970 as The Forest Railway, which this year carried its three millionth passenger.

In 1986, Prince Charles officially opened the rebuilt Thorburn Gallery, named after a famous wild-life artist. His paintings no longer hang on the walls but they can be

The Queen of Nebraska steams into the station at Dobwalls



rest of the to follow'



experienced in the context of the 'see, touch, feel, smell' cameos of the scenes which inspired them.

A Soundalive Audio Tour commentary designed for blind and partially sighted people includes descriptions of paintings they cannot see, including the colours - research having shown that even people who have been blind since birth require this information as part of their general knowledge.

Dobwalls has a discounted holiday scheme for people who through disability or low income would normally be unable to take a break. This year, 200 people enjoyed discounted off-peak holidays under the scheme.

There are a disabled toilet, low light switches and self-service counters, with a selection of electrically-driven and manual wheelchairs available on free loan. There is a yellow-banded 'easy access' route around the park, also used by parents wheeling children in prams and pushchairs.

The only building which is not wheelchair-accessible is the Denver Diner, an elevated cafeteria overlooking the railroad. But the Queen Victoria Tea Room is easy to get in and out of.

Admission at winter rates until the beginning of April are adults £2.50, children £1.50 and family and party tickets. Groups of disabled people get in for £1 a head. The park opens daily at 11am, with last admissions at 3.30pm. Tel 0579 20325 for more information.

Wheelchair-friendly hotel in Wales

The 20-room Jane Hodge Hotel, in the heart of the Vale of Glamorgan, was opened this summer by John Grooms Association for Disabled People at a cost of £2million.

It has an indoor swimming pool, sauna, Jacuzzi and full sports facilities - plus everything that physically disabled people need to enjoy a relaxed, refreshing holiday. Round-the-clock care is available if required.

There are pleasant grounds with patio and barbecue areas, plus a giant chessboard for guests with an intellectual turn of mind!

Tucked away in peaceful Trerhyngyll, work started early in 1989 on the site of the old Jane Hodge Home. The buildings and its surroundings are all completely wheelchair-accessible.

Nearby is the market town of Cowbridge, with Swansea and

Cardiff not far away along the M4. The Gower peninsula, with its glorious coastline, is a short trip away and there are many other places of interest - including the famous Welsh castle.

The judges said: "This is a hotel of the highest quality and, in customer care, a long way from the institutionalised holiday traditionally provided."

Contact John Hartley, tel 081 800 8695, at John Grooms headquarters for further details.

Carving out a warm welcome

Dorothy Thomson and her husband Peter have a wood workshop with space for up to four students at a time, including one in a wheelchair, at their Mill Croft Guest House - 25 miles from Aberdeen. All those wanting an activity holiday learning woodcraft get individual attention. That includes lathe work, veneer work, carving and marquetry. "It helps to keep the



A view inside the Mill Croft wood workshop.

mind alive while relaxing," said Mrs Thomson.

If you like your holidays untrammelled by the madding crowd, this is the place to be. There are only three bedrooms, with one room with a double bed that is suitable for people with wheelchairs. The couple make it available to single people at the same rates.

Dining room/lounge, bedroom and shower/toilet facilities are all on the ground floor with easy access. The shower is next to the bedroom, but not en suite. The car park, patio and walkways are level and paved, and the Thomsons will collect and return their guests to the rail and coach stations.

The judges commented: "A most delightful example of genuine customer care and attention." Details, tel 046 45 210.

Messing about on the river

Get out your yachting cap and be captain of your own vessel - on board what is believed to be Europe's first wheelchair-accessible luxury hire cruiser.

Charlie Park, owner of the 12-boat Erincurrach Cruising fleet near Enniskillen, Co Fermanagh, has converted one 37ft craft with a flying bridge to give disabled sailors the time of their cruising lives. Wheelchair users can steer the craft from inside the cabin.

There is ramp access cut into the top superstructure with a hydraulic helm seat and lift to the lower cabin,

toilet and galley. "We didn't want disabled people to have to endure the embarrassment of being hauled about in slings", said Mr Park. The boat can accommodate up to two wheelchairs at a time.

In the judges' view "every member of the family, including wheelchair users, would have a great time."

The boat is named 'Cuchulainn' after an Irish warrior of old and, once aboard, there are 52 miles of beautiful waterways to explore.

Telephone 08206 26267 for information.

'Accessible' symbol - latest awards

Forty hotels, guest houses and self-catering properties have been awarded the new Tourism for All Accessible symbol since the scheme was launched by the Holiday Care Service in the summer.

The purpose of introducing the new symbol was to ensure that visitors with impaired mobility can obtain reliable and consistent information about accessibility. The Hotel and Holiday Consortium, representing tourist boards and disability organisations, has drawn up a minimum standard for accommodation which must be met before the symbol is awarded.

These include:

* A public entrance accessible to disabled people from a setting-down or car-parking point

*Reservation of space for a disabled guest on request

*Disabled people must have access

to the reception area, restaurant or dining room, lounge, TV lounge (unless a TV is provided in bedroom) and bar

*A minimum of one guest bedroom with bath-shower and WC facilities en suite, suitable for a wheelchair user, must be provided. Where bath/shower and WC are not en suite, a unisex WC compartment and a bath/shower room suitable for a wheelchair user must be provided on the same floor level.

SYMBOLS AWARDED SO FAR

England

London Tara Hotel, Scarsdale Place; Brissenden Court, Kent; Post House Hotel, Sevenoaks, Kent; Saint Leonard's Hotel, Near Ringwood, Hants; Elstead Hotel, Bournemouth; Cophorne Hotel, Plymouth; Holiday Inn, Bristol; Nelson Hotel, Norwich; Norwich Hotel, Norwich; Swallow Hotel, Peterborough; Heyford Manor Hotel, Northampton; Whitewells Farm, Malvern, Worcestershire; Kingstown Hotel, Kingston-upon-Hull; Hoole Hall Hotel, Chester; Shellard Hotel, Blackpool; Kielder Adventure, Hexham, Northumberland; Plawsworth Farm, Chester-le-Street, County Durham; Royal County Hotel, Durham City, County Durham; Travelodges throughout England.

Wales

Bryn Glas Hotel, Trefant, Clwyd; Hen Ysgol Holiday Homes, Anglesey; Richard Wilson Arts Centre, Caernarfon; Royal Victoria Hotel, Llanberis, Gwynedd; Gorslywd Farm, Tan-Y-Groes, Cardigan; Scubor Wen Cottage, Whitemill, Carmarthen; Broad Haven Youth Hostel, Haverfordwest; Rocksdrift Apartments, Haverfordwest; Rosedene Guest House, Hodgeston, Near Pembroke; Stackpole Home Farm, Hundleton, Pembrokeshire; Gaer Cottages, Lampeter, Dyfed; Castle of Brecon Hotel, Brecon, Powys; Jane Hodge Holiday and Activities Centre, Treerhyngyll, South Glamorgan; Surf Sound Guest House, Gower, West Glamorgan; Travelodges through the Principality.

Scotland

Irvine Hospitality Inn, Ayrshire; Edinburgh Sheraton Hotel; Rosslea Hall Hotel, Rhu, Dunbartonshire; Atens Skean Dhu Hotel, Aberdeen; Travelodges at Dumbaron and Gretna Green.

Charlie Park's wheelchair-converted craft near Enniskillen. Super for messing about on the river!





KEEPING UP APPEARANCES

Karen Desborough is a fashion designer for able bodied and disabled men and women. She believes appearance is important and gives her tips on how to achieve the look you want.

Did you know that we all make assumptions about each other within the first three seconds of meeting? And these assumptions are based just on the way we appear. This is one of the reasons why our clothes and appearance are extremely important. This is particularly so for those who have a disability - as we want everyone to see the person and not the disability. If we remember this we can decide whether we are giving the impression that we want - be it professional, casual or outrageous.

These factors become even more important when going for a college or job interview or special social occasions. We should dress for the occasion but also to please ourselves and to project the image we want. Clothes can enhance, project, or even cover-up our personality. You may meet someone who comes across as aggressive and self-confident because of the way they dress and then find, when you get to know them, they are actually quite shy and passive.

However you decide to dress it should always be clean and tidy. You don't have to spend large amounts of money to look good - use markets, jumble sales, seconds shops, Oxfam, and sales in department stores and catalogues. And if you feel good and comfortable in something you've had for years, keep it. Don't worry if it's not the 'height of fashion', you can bring it up to date with a little imagination and the right accessories - hats, gloves, jewellery, scarves, socks, shoes and ties can add a new

dimension. Your hair and make-up also need to be considered.

Keeping warm is important to us all. It is better to wear many thin layers of clothing rather than one thick layer - warm air is trapped between the layers. Natural fabrics such as wool, cotton, silk and linen are generally warmer, though more expensive than man-made materials. But new man-made fabrics have been and continue to be developed which are warm. There are mixtures of man-made/natural fabrics which combine the properties of both materials and wash well.

For those of us in wheelchairs the need to keep our legs warm must not be overlooked and woollen tights or socks or thermal leggings underneath skirts or trousers are a good way of doing this.

When looking for a new outfit, even when going to jumble sales, take a tape measure with you because trying on clothes in a cubicle can be near impossible.

There are many adaptations which can be made to clothes to make life easier and give a better fit. Having elasticated waistbands, using velcro instead of buttons, putting insertions in trousers and reinforcing areas of wear. If callipers are worn you may find loose fitting trousers are suitable. Some girls may find that modern open-fronted maternity trousers are more comfortable and practical for them to wear.

The size of garments is another

practical consideration - having one size larger than you need may be more comfortable and make dressing easier. And deliberately 'oversized' clothes are fashionable at present. If you need different sizes to fit your top and bottom half properly, why not buy separate tops and bottoms - I know that men's suits can be brought in this way. If this still doesn't provide a good fit then you can get garments made specially for you.

Patterns are significant when choosing clothes - horizontal stripes make the area which they cover look wider, vertical stripes can make the same area appear narrower. So if you are a little on the larger side, or just want to appear thinner, wear a vertical stripe or pattern. If you are small and/or short it is usually best to wear a small rather than a large pattern.

Whether you want to change your image or just enhance your appearance it is generally a good idea to concentrate on your good points. Everyone has them, perhaps it's your hair, hands, eyes, shoulders, waist - if you're unsure about your best features ask someone you trust to help you decide or have a long look in the mirror. You may decide to show off your bubbly personality rather than a physical feature but, anyway, why not experiment with as many different looks as you can, and try different colours - even those you've not thought of wearing before.

I hope I will not offend anyone but I have to say that I have come across disabled people who dress unsuitably, either because the clothes are the wrong size (too tight) or have been chosen for them by an older parent or carer, or they are wearing styles which are not really suited to their age group.

It is extremely important that you are happy with your own appearance and as long as you are clean and tidy you should not be too bothered with what anyone else thinks. Just be yourself!

From the men's point of view

We all know how important the fieldworkers are to ASBAH's service to its clients, as they are in the frontline supporting parents, children and young people. Throughout the country we now have 43 fieldworkers but only three of them are men and as Teresa Cole, fieldwork manager, says this is more than ever before.

"ASBAH has only ever had three male fieldworkers - the ones now in post, with Tom Davies joining us over 10 years ago. There was a fourth chap, briefly, but he was on secondment from a bank."

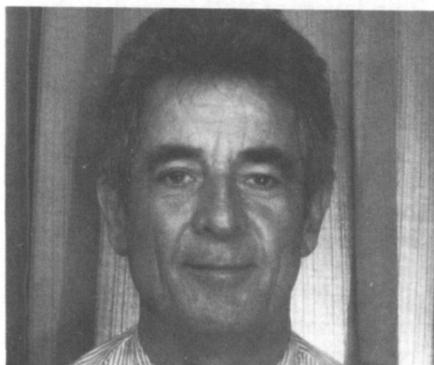
How do these three men view their part in the fieldwork service? Tom, Alan and Karl tell us about themselves and their work.

Tom Davies

Tom is our longest serving male fieldworker, having joined us 12 years ago. When he started - apart from the fieldwork manager at that time - he was the only man on the team. But he's "never felt out of place". At first it was the part-time hours and working from home which he found strange. Tom missed the daily colleague contact he'd had as a social worker but he came to find working from home an advantage, making him more independent and able to work in his own way. The support from his fieldwork colleagues has, nevertheless, "always been strong" and they do meet several times a year on a regional basis and three times at National Office.

The approach to his work with ASBAH's clients is "softer" than when he was a social worker. Then he dealt mainly with young offenders and this involved a lot of court work. His case load did also include some youngsters with disabilities and, when the ASBAH post became vacant in South Wales, it gave Tom a chance to change direction and pursue this area of work.

He gets a rather different reception from families he visits in his work for ASBAH. As a



social worker he was often seen as "someone from the council" but now parents treat him more like a friend. And it was through his contact with our families that he met his wife. His wife's sister had a baby with spina bifida; Tom got to know the family and was invited out to Venezuela (their native country) for a holiday, where he met his wife.

Three years ago Tom became a full-time fieldworker. He tries to plan his week ahead but it "doesn't always work out that way" as the unexpected crops up. He says he doesn't have a 'typical' day - he could be visiting hospital all day, concentrating on one family, or seeing up to five different families in their homes. He enjoys the variety of his work and though it can be "exhausting, it's also rewarding".

Tom "lives in his car" during the week and so at weekends he likes to walk, especially along the coast. Having recently moved to

a new house with his wife and young daughter, he's also got plenty of DIY to keep him busy.

Alan Langshaw

St Helens is Alan's patch which he describes as "an industrial and bustling little town on the north east edge of Liverpool". Most of his families live within a fairly small area which has given Alan the advantage of being able to "get to know the area extremely well and use the available resources without having to go far to find them". He has a very active and supportive local association and is able to use their "specialist knowledge and skills" too.

Although he's only contracted to work for ASBAH for 10 hours per week "like all other fieldworkers"



he actually works many more hours to get everything done. But Alan also has another job - "When I'm not working for ASBAH I work as a lecturer in social care and in the special needs section of Halton College, Widnes". At the college Alan also teaches drama - one of his many skills from which ASBAH members have benefited - his drama sessions at mobility weeks are always popular.

When he first became a fieldworker Alan says he was "disappointed to find that there was only one other male worker in the team. I am very pleased that Karl has now joined the ranks too. Throughout my career I have always been concerned about the notion that women somehow have a monopoly on caring - it appears to be a reverse sort of sexism. I think that we often put the wrong impression across to those for whom we care by perpetuating the myth that only females can care or be emotional!"

But Alan appreciates that the reason for so few male fieldworkers is more a practical problem, with most fieldworkers being employed part-time - a sentiment shared by our fieldwork manager.

"I would be delighted to get more applications from men wanting to be fieldworkers but the difficulty is that most of our vacancies have in the past been for part-time posts, and most men are looking for full-time work" says Teresa Cole.

Despite having two part-time jobs which add up to more than a full-time occupation, Alan says he does get "some spare time" and as with his work he packs a lot into it. He enjoys theatre and counts working with an inner city drama group as relaxation. He likes watching sport and proclaims a "passion for Tranmere Rovers". Despite being in the heart of Rugby League country he admitted, exclusively to LINK, that he really prefers Rugby Union and follows St

Helens. Like his colleague, Tom, he enjoys walking and does so along the coastline near his home in the Wirral.

Karl Hottt

Karl followed in the footsteps of the redoubtable Meg Garnett when he became our fieldworker in Suffolk. Meg had worked the patch for 12 years before her retirement. Wherever Karl went, her name cropped up. "Meg had become almost a household name", said Karl - who joined our fieldwork service in June. "Not only had I such a hard act to follow, but people were looking at me - a mere male - rather curiously. And when their first words invariably were 'So you're Meg Garnett's replacement', I had to make it clear that I would be doing things my way", he remembered.

Karl refuses to be intimidated by the traditional image of an ASBAH fieldworker as a middle-aged woman driving round the country in a battered Metro. In fact, like many of his female colleagues, he works part-time, and the hours suit. He works from home near Newmarket and fits the job round a business

which he runs with his wife, Judy.

The couple keep chickens and goats on a smallholding. They supply goats milk and cheese to delicatessens in and around Cambridge.

"The hours are very convenient, but I also like the autonomy of the job. You are not restricted in what you can do to help, as you would be working in a social services department", says Karl, "I must admit I still find it strange not leaving the house to go to work, but going up to the back bedroom."

Females rule Karl's home life. He and Judy have two daughters - Rebecca (two) and eight month old Jessica - and Rebecca gets a kick out of bursting in on dad at work.

He says he runs the goat herd as an equal partnership with Judy. And he'll do his share round the home - particularly when Judy returns to work soon as a part-time teacher working with hearing-impaired children.

"I've got the best of both worlds, a fascinating job and one which gives me plenty of time at home".

Karl with his wife Judy, and their two daughters



MOVING TOWARDS ACCESSIBILITY

Bert Massie, Director of Radar, looks back over the decade and assesses what progress has been made in making transport more available to disabled people.

In June 1980 the Department of Transport began to prepare for the following year's International Year of Disabled People. The first initiative was a meeting at the Department, of voluntary organisations concerned with the mobility of disabled people. Ten years later it is possible to reflect on both the positive results of that meeting, and how much remains to be done.

Progress - on taxis

In 1980 the Royal Association for Disability and Rehabilitation (RADAR) argued that taxis should be accessible to disabled people, including wheelchair users. This had long been RADAR's policy and can be traced back to a report published by the Central Council for the Disabled. The initial response from the taxi trade was that this would be impossible. Undeterred, the Department of Transport approached the company which manufactured the standard London taxis. They agreed to see if they could design a taxi suitable for wheelchair users. About a year later a mock-up was ready for testing. It seemed ideal but problems occurred during the production process and in the end the taxi was never produced. The accessible features were, however, incorporated in the current Metrocab which is now to be seen on the streets of many of our major cities. Once it was possible to make the traditional black taxi accessible, the Government altered the regulations concerning access. At present, all new taxis have to be accessible to wheelchair users and, as from 2000, it will be unlawful to use an inaccessible taxi in London. Further work is

taking place to improve the taxis for use by ambulant disabled people.

Thus, in the course of ten years, we have moved from being told emphatically that it was impossible to make the necessary adaptations to the acceptance of accessible taxis as part of everyday life. A huge success.

Progress - on trains

At about the same time, British Rail appointed an advisory body to promote facilities for disabled passengers. One of its first successes was the introduction in first class carriages of a designated space to enable a wheelchair user to travel in comfort in his/her wheelchair. In addition, some standard class carriages now have a similar wheelchair space available and an accessible toilet. Other improvements which we still need include: better colour contrasts on trains; better announcements for blind passengers; and more visual signs for hearing-impaired people. In general, however, BR has made remarkable progress. What's more, it has involved disabled people in all the discussions and plans - a good example of what other transport operators should be doing.

Progress - on buses

One of the greatest demands from disabled people is that

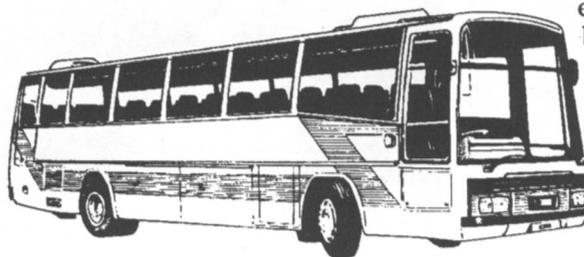
buses should be accessible. The Disabled Persons Transport Advisory Committee (DPTAC), which was established by the Transport Act 1985, has produced specifications to make buses more accessible to the four million people who have a mobility handicap and who do not use wheelchairs. The specifications have been widely welcomed by disabled people and, crucially, by bus operators. Better facilities mean more passengers which equals more money for the bus operator. We must now move forward to cater for the half million wheelchair users, and work is taking place to determine the best way to do this.

Through its membership of the European Conference of Ministers of Transport, the UK Government is committed to introducing accessible buses. Discussions and tests are currently going ahead to decide whether lifts should be installed on buses or whether a better option would be to have low floor buses which everyone, including wheelchair users, can get on and off easily.

Could do better?

The problem of access is more acute on coaches. They seem to be designed more for suitcases than for people! As coaches need high floors for sightseeing purposes and to store luggage at a low level, the only rational answer appears to be to fit them with lifts. RADAR believes that there should be action to make coaches accessible so that disabled travellers can have a genuine choice between the faster railway network or the slower but less expensive coach network.

Even if public transport is made accessible to disabled people there will still be the need to enable people to travel between transport modes. Developments in recent years on textured pavements and dropped kerbs have made urban mobility much easier for disabled people. But even with a completely



accessible environment there will be some people who require the specialised services of Dial-a-Ride schemes or a Taxicard scheme to subsidise taxi travel. Sufficient funds must be found to finance such schemes and sufficient managerial expertise introduced to ensure the best value for money is obtained so

that as many disabled people as possible are able to use the service.

Many of the improvements we have seen in the last decade were pipe dreams in June 1980. Although complete success has not yet been achieved, the way ahead is clear. Perhaps the reason

for this success is that Government, voluntary organisations and transport operators have made a positive and active attempt to understand each other's needs and problems, and to seek solutions. It is an approach which has produced results, and will produce yet more.



A TALE OF TWO JOURNEYS

Our second article on improvements in the transport system for disabled people is from Roy Thompson, a disability consultant. He was recently invited to take his first train journey in 35 years to keep him informed of British Rail's latest policies. His personal experience echoes many of the sentiments expressed in Bert Massie's overview - that there have been improvements for the disabled traveller but more are needed, particularly to enable people to travel between transport modes.

On Wednesday, 27 April, 1955, I travelled by train from London, Paddington to Birmingham, Snow Hill, just four days away from my retirement from the army and the beginning of my AA management training period at Maidstone.

The purpose of the visit was to collect my first motor car, a Ford Popular, ROJ 406, suitably adapted with hand-control. Little did I think then of the trauma that was to lie ahead of me on my arrival at Snow Hill.

Having brushed all offers of assistance aside, I began the process of descending from train to platform - a drop of two feet and a jump through my elbow crutches, hopefully landing on my two feet - but, alas, that was not the way it was to be, for with sticks on platform and my feet at the carriage door, the train suddenly shuddered and started to move forward.

Panic-stricken, I heard shouts of "jump!" and, as I did, a man ran forward and in the melee I landed on top of him.

My mother had ignored my wish that I did not want anyone to meet me on this my first journey solo after my illness and her voice was heard loudly shouting "His rug...his case..." and a second railway official jumped on to the moving train and out came my rug rather like a Turkish carpet, smothering my rescuer

and me, the case only just missing our heads.

My indignation was complete, my plan had gone hopelessly wrong, and I showed my wrath at the inefficiency of British Railways by stampeding the length of Snow Hill platform to the goods lift and my taxi.

It is hardly surprising, therefore, that for 35 years I never travelled on a train - until Tuesday, 17 July 1990, the very week that the Director-General urged us all to think about the use of our motor cars. Obviously, the adviser for disability to the Chairman of British Rail thought that my record was unhealthy and one which could come to an end and so, with much ceremony, I arrived at Reading station to

begin what was to be an exciting and memorable journey of 36 miles to London, Paddington.

I had on several occasions in the past demonstrated in the wheelchair how to board a train - but before there was any movement I had dismounted.

This time it was the real thing. With no difficulty whatsoever, a portable ramp as part of normal



platform equipment was unfolded and within half-a-minute I was in the allocated position for a wheelchair traveller in the rear carriage. The train was under way.

Only 20 minutes later, this Inter-City train came to a halt at Paddington Station and my 'Boys Own Paper' story had a happy ending as the guest at lunch of the British Rail Board in the Great Western Hotel, Paddington.

There is no doubt that the appointment of a disabled adviser to British Rail, who is himself disabled and a railwayman of distinction, has resulted in much more positive thinking than in the past.

Generally, the facilities to enable disabled people to travel on trains are much improved with station parking facilities and level access to platforms by bridge and lift. If the days of being consigned to the guard's van have not gone, they are disappearing: there is space in a carriage for a wheelchair, with a lift-up bucket seat for use by the able-bodied when not otherwise required. There is still room for improvement, but trains are being designed sympathetically; for example to enable washrooms to accommodate a wheelchair.

As a motorist, however, there is an additional moral to this story. On my arrival at Reading, all the allocated spaces for disabled drivers had been taken. Parking the car, taking out the wheelchair and travelling to the platform to the point of entry to the train took 19.5 minutes as compared with the 20 minutes to complete the 36 miles. There certainly is a requirement for disabled drivers to respect the concept of a nationally co-ordinated transport system but it is hardly feasible, if, in fact, there is not proper access provision at railheads or other termini for motorists, disabled and able-bodied people alike, to park their cars.

Our thanks to Radar's Contact magazine for the article by Bert Massie and to the Automobile Association for Roy Thompson's story, which first appeared in their Fanum news.

MAJOR ARTICLES WHICH HAVE APPEARED IN LINK DURING 1989 AND 1990

The major articles which have appeared in LINK during 1989 and 1990, issues 120 - 130, are listed below. If you would like a copy of a particular article send your request with a stamped, addressed envelope to Miss Pat Corns at ASBAH's National Office.

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Community care grants

Lynne Young, ASBAH fieldworker for Cornwall, writes this article to remind readers that they may be eligible for a grant to help them cater for their special needs.

"Are you disabled and receiving Income Support, or are you the parent or carer of a disabled child and in receipt of Income Support? If so, read on..."

In April 1988, the Social Fund was brought into force and replaced the old Department of Social Security grant system. Under the Social Fund rulings, Community Care Grants were made available to promote community care and help people live as independent a life as possible.

If you have special needs because of your disability, community care grants are available to provide various items to enhance the quality of your life. The minimum grant is £30. Listed below are a few examples of items for which you might be eligible for a grant. If in doubt, apply.

Moving into your own home? If so you could apply for a grant to help you to purchase furniture, bedding and household equipment. The maximum grant for a single applicant is £500 and, for a couple, £750.

Grants may also be available for the following items if you experience any of the problems indicated:

- * clothes - if these wear out quickly

from frequent laundering because of continence problems, or if callipers cause heavy wear on clothing

- * bedding - incontinence may mean bedding has to be changed frequently, or you may need the extra warmth which could be provided by a duvet, for example

- * washing machines/tumble driers, again may be particularly necessary if you have continence problems. Although you may be able to get a grant for the purchase of a tumble drier bear in mind that it could prove expensive to run

- * interior decorating - if you spend a lot of time in your own home because of your disability and are unable to do your own redecorating then this is another area where you may be able to apply for a grant

- * mattresses - if you get pressure sores it may be possible to get a grant for a Spenco mattress

- * educational toys - grants may be available for toys such as shape sorters and activity centres if your young child has learning difficulties associated with hydrocephalus and needs stimulation through play.

How to apply

Contact your local Social Security office and ask for application form SF300. You do not have to complete

the form in the DSS office - take it home with you, or ask for the form to be posted to you. Ask for help in completing the form if needed.

Do not ask for a budgeting loan - these have to be repaid.

It is often helpful to send a letter with your application - from any professional with whom you have regular contact. Perhaps your fieldworker, social worker or health visitor would be willing to provide this for you.

When to apply

Each local DSS office has a monthly budget. If you apply on the first of the month, there should be funds in the budget. If you wait until the middle or the end of the month, you may get turned down.

You cannot make a repeat application within 26 weeks of a previous application for the same item unless there has been a change in your circumstances.

If you have savings in excess of £500, Community Care Grants will be reduced by the extra savings. For example, if you have £575 in savings and are awarded a Community Care Grant of £142, the actual award will be cut by £75 and you will actually receive £67.

Remember, do not settle for a budgeting loan and if the form confuses you, ask for help."

SDA and training allowances

ASBAH's National Office has received a number of enquiries as to what effect a course with an allowance may have on severe disablement allowance (SDA) - Teresa Cole, fieldwork manager, offers the following advice -

- ◆ If the money offered is a training allowance then this does

not affect SDA.

- ◆ If the money is said to be an allowance for employment training then this is usually about the same rate as SDA plus £10.00 and it should not make any break in SDA entitlement.

In the above circumstances we understand that the training allowance is not taxable nor subject to national insurance.

- ◆ In the event of being offered a course, it would be best to clarify precisely what they say the actual allowance is supposed to be: is it

a training allowance, employment training or is it "wages" of some kind?

- ◆ It would be wise to keep a record of days off while on the course, any difficulties experienced, any concessions made due to the disability, what supervision is given and what support is available. This will enable a record to be available at any time if the DSS decides to challenge the SDA.

◆◆◆

If anyone does have problems with SDA and training allowances please let us know.

Service for disabled drivers

The Royal Automobile Club has introduced a service specifically for disabled drivers. Called Response, the new service is for orange badge holders and is designed to "meet the needs of the disabled motorist, providing a flexible, individual solution to their problems when their car breaks down, and ensuring that they are able to continue their journey with the minimum of inconvenience" says their services director.

In the event of breakdown a free phone call to the computerised control centre of the RAC will alert them that this is a response member who may therefore have special needs.

For those unable to leave their cars after a breakdown a 'Help' distress pennant is provided, to attract assistance, plus a breakdown details pad which can be given to a passer by to contact the RAC with the correct information.

Members who break down can agree with one of the RAC's Personal Incident Managers which of the following options would be most appropriate if their vehicle cannot be repaired on the spot:

* onward travel by public transport or taxi, paid for by the RAC up to £100 per individual -



with a maximum total of £300 if a party is travelling together.

* use of an automatic hire car for up to three days, subject to availability - though vehicles with hand controls would not be available

* overnight accommodation arranged locally by the RAC at a hotel with suitable facilities, costing up to £300 for a disabled traveller and his party.

The fee for the RAC Response service is £64 per year, plus a once only joining fee of £10 for new members, this covers one nominated vehicle for any authorised driver. Personal cover for the member and spouse travelling in any vehicle as either a driver or passenger is automatically included. A complimentary copy of 'On the Move' - an RAC publication with useful information for disabled travellers - is also part of the membership package. For more details, contact: *RAC Member Services, PO Box 700, Spectrum, Bond Street, Bristol BS99 1RB*

Continence conference

The association of continence advisors is holding a national study day in January on faecal soiling in childhood. The conference will bring together the leading clinicians and researchers in this field and it is aimed at a wide audience from the fields of child health, general practice, nursing, psychology and social work.

The study day is being held at The Conference Forum, London on Thursday, 24 January and amongst the speakers is ASBAH's continence adviser, Mary White.

The fee for the day is £30 for ACA members and £40 for non-members, including lunch, refreshments and an information pack. For further details contact ACA on 071 266 3704.

Railway Lines

Each of London's nine mainline railway stations has a special telephone line for use by disabled travellers requiring help or assistance. The numbers are:

- ◆ Euston - 071 922 6476/6482
- ◆ Kings Cross - 071 922 4904/4901
- ◆ Liverpool Street - 071 928 5151 ext 52789
- ◆ London Bridge - 071 922 4548
- ◆ Marylebone - 071 922 6543
- ◆ Paddington - 071 922 5151 ext 31083
- ◆ St Pancras - 071 922 6466
- ◆ Victoria - 071 922 6215
- ◆ Waterloo - 071 922 4500

More mobility bus routes

Eleven new wheelchair-accessible bus services have been introduced in Barking, Havering and Redbridge by London Transport. This is the sixth of LT's networks of mobility buses, joining the 45 other routes in various parts of London. For more details of times and routes contact the travel information service on 071 222 1234.

New man at London Transport

On 2 January Mr Andrew Braddock joins London Transport as Head of the Unit for Disabled Passengers, succeeding Tony Shaw who is retiring after more than 40 years with LT.

Mr Braddock is a member of the Disabled Persons' Transport Advisory Committee's Bus and Coach Working Group and of 'Tripscope', the organisation which provides a travel information service for disabled travellers.

Diary dates

16 January - Parent Information Day on play and leisure activities for children with special needs. Newcomen Centre, Guys Hospital, London. Fee £2.50. Contact Janet Badcock on 071-955 4636 for details.

23-27 January - Music, Art and Drama Workshop, a course for all categories of staff working with children and young people with special needs, to be held at Castle Priory College, Wallingford, Oxon. £199 inc accommodation, tel: 0491 37551.

28 January - The London Disability Arts Forum presents "Workhouse" - a disability arts cabaret. The Oval House, 52-54 Kennington Oval, SE11 at 7.30pm. Tickets £3.00. Venue is fully accessible. More information from LDAF on 071 935 8999.

15-17 February - Citizen Advocacy - a course for those wishing to develop, or who are involved in, citizen advocacy projects. Castle Priory College, £169.

Sporting opportunity

Keen young sports people should make a note in their new 1991 diaries - the week beginning 15 April 1991 when the National Star Centre for Disabled Youth is holding a sports course for 14-17 year olds who have a physical disability. There will be national coaches at the three day residential course and sports will include wheelchair basketball and rugby, table tennis, swimming, tennis, boccia, archery and athletics. The venue is a specialist residential college which claims to have superb sports facilities. The cost is £10, including full board, coaching, and a resource pack. Care attendants will be available. For more details contact the Vice Principal, National Star Centre College of Further Education, Ullenwood, Cheltenham GL53 9QU. Telephone 0242 527631.

Sweden calling

IN OUR last issue we promised to keep you up to date with information on the 1991 conference of the International Federation for Hydrocephalus and Spina Bifida (IFHSB) which is being held in Sweden in August. As we mentioned then, organisers are hoping to attract the families of those attending the conference to make it a holiday too. They've included a programme of sports and social activities for the whole week for young people aged 13 - 25 years to be run as a summer camp.

We now have information on what will be happening in the exhibitions in the five 'houses' - each an activity unit for a different spina bifida/and or hydrocephalus related issue - here's a brief outline of what they will cover:

Hygiene House

- problems and practical solutions to incontinence, with demonstrations of catheters, underwear etc
- personal hygiene and hygiene at home - bathroom equipment, cleaning and laundering and an exhibition on how the problems are tackled in various countries

Nutrition House

- appropriate diets to promote good health in youngsters who are wheelchair users
- opportunities for parents to collaborate with student dieticians on ideas for recipes and menus

School House

- a team of teachers and parents

will man this 'house' to cover learning issues

- adapted toys, games and teaching aids will be demonstrated

- equipment and practical solutions for classrooms

Sports and Leisure House

- wheelchair training for sports, individual modification of wheelchairs
- sportswear and equipment
- games and competitions
- exchange programmes run by Phab international

Fashion House

- fashion show
- how to modify clothes, aids for sewing and altering.

Costs

The price to attend the Congress itself, from 14-18 August, is 2,500 SEK (approximately £250) and includes accommodation and meals.

The Family Week and Young People's Programme (for 13-25 year olds) begin earlier - on 11 August - and continue for the whole week. The cost of the Family Week includes accommodation, meals and participation in the Congress, adults pay 4,500 SEK (£450), 12-18 year olds, 2,000 SEK (£200), though they are hoping to bring the latter price down, and for children under 11 years old it's free. The 'camp' for 13-25 year olds cost 2,500 SEK (£250) each and again accommodation and food are in the price, as well as all camp activities.

A registration fee of 25% of the total has to be paid in Swedish Krona to Gotabanken Swift, Gotasesj No: 4264-100 192 -2 by 31 March 1991. The total must be paid before 31 May.

In the next issue we'll give information on ways, and likely costs, of getting to the Swedish Archipelago for the Congress.

Integrated Education

Tony Britton reviews
'One Step at a Time'

M

argaret Slade's book 'One Step at a Time' is bound to cause hackles to rise in some educational establishments.

A former nursery nurse, whom many would regard as near to bottom in the school pecking order, she shows how she persuaded schools in which she worked to modify their practices in order to integrate their first disabled pupils.

Mrs Slade retired a couple of years ago. She has used her spare time since then to turn out a readable account of a well-spent 18 years at two schools in north Wales - watching out for pupils with a wide variety of physical disabilities.

Neither school had attempted before to cater for children unable to run with the crowd, prevented from charging up the stairs and needing extra time to attend to their toilet or cough their lungs clear of mucus.

The author was employed to be the classroom helper for a little girl with spina bifida and hydrocephalus from the moment she entered junior school. She followed her special charge right through comprehensive, learning, from early mistakes, how to recognise difficult situations often before they arose and when to stand back and let the child just get on with it.

In the process, the large comprehensive school learned how to provide real education for everyone. A number of other pupils with disabilities were later enrolled, including children with cerebral palsy and cystic fibrosis. Mrs Slade, who first suggested the idea of a small 'home base' where they could all meet and relax during the day, got to know all the children well.

Mrs Slade insists that St David's School, Clywd, could never have achieved integration without the support of a kind and caring head teacher. But it is equally clear the school derived its strengths in this field from a committed team of people which sought little in the way of personal reward or status - its nursery nurses and welfare assistants.

The book is not political with either a big 'P' or a little one, far from it. Mrs Slade is too concerned to be true to her experiences and to be generous to those who helped her achieve job satisfaction to distort the facts to fit a slanted view of work.

She does, however, speak up for nursery nurses who not long ago were told to leave school at the age of 21 after working mostly in reception classes. Only recently have they percolated through to secondary schools, and obtained a semblance of professional recognition.



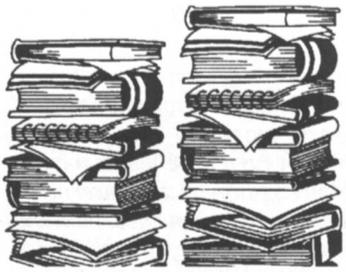
Mrs Slade says they need job satisfaction, to earn respect and to know, and to be told, that they are good at one's job. Even though there is no structured promotion ladder to climb, they are an unusual breed in that a friendly word of thanks will still compensate for lack of material reward.

'One Step at a Time' is well worth reading by any teacher, school governor or parent wanting to know more about educational provision for children with special needs, and how theory translated into practice in one part of the country.

Not every professional working in the field will agree with all of Mrs Slade's conclusions about the long-term effects, for instance, of hydrocephalus on the personality, particularly as her data is based on such a small sample of children. But her ideas are well presented and the point is that we are all on a learning curve.

Some may mutter that this book is the tail attempting to wag the dog. But the dog would feel lost if it did not have one to wag.

'One Step at a Time', only from Maysdale Books, 63 Ffordd Glyn, Coed Y Glyn, Wrexham, Clwyd LL13 7QW, price £4.95 including postage.



BOOK SHELF

'You and Your GP'

A handbook for patients'. This book aims to help the patient know how to insist on the best care from the GP, and not just by shouting at the doctor. There is room, apparently, to build up confidence on both sides. If confidence breaks down, however, author Kathleen McGrath tells how to transfer with as little pain as possible from one doctor to another.

Contains a small glossary to explain some of the more common jargon often misheard in

a doctor's surgery, but you still might need to take a medical dictionary in with you. Published by Bedford Square Press, publishing arm of the National Council for Voluntary Organisations, at £4.95.

'Eliminating Shadows'

A manual on Photography and Disability by Ray Cooper. This book contains over fifty illustrations, helping to show how disabled photographers can gain practical solutions to their photographic problems. It contains information on the

advantages and disadvantages of many items of standard equipment and gives hints on what non-standard equipment may be of use to particular individuals. The book is available from the Paddington Printshop, 1 Elgin Avenue, London W9 3PR, at £12.95 plus £2 p&p.

'Choosing for Children'

Parents' consent to surgery', by Priscilla Alderson, published by Oxford Paperbacks at £6.99. Looks at the moral, ethical and personal dilemmas of consenting to high-risk medical and surgical treatments for seriously ill children, seen through the eyes of the parents.

This is the other side of the coin where surgery is considered inappropriate because children are too ill, as portrayed in 'Love and Loss' by Eileen Delight and Janet Goodall (ASBAH still has copies of this publication, priced at £5 each).

High Profile for ASBAH at NAIDEX

Hundreds of visitors stopped to speak with ASBAH staff at the NAIDEX exhibition held in October.

Thousands of people thronged through the doors of London's Alexandra palace to this annual exhibition of aids for disabled people and the elderly.

There were nice touches from the organisers – a courtesy bus from the car park half-a-mile away and another all the way from Euston Station but visitors still faced a climb up a long flight of stairs to the terrace, and uneven floors.

Pictured: ASBAH accommodation officer, Dominique Cull talks to a visitor while a group from Sussex ASBAH watch a video about a wildlife course at our Five Oaks Centre in Yorkshire



Executive appointment

Our committee have expressed amazement and concern at the salary of "not less than £30,000" being offered for the new chief executive of ASBAH as revealed in the October edition of Link. Whilst we appreciate the importance of the position, such a salary seems excessive in comparison to the many hours of voluntary, unpaid time which many of the local associations' officers put in to support their members.

We fully understand that ASBAH wishes to attract the best person for the job but, as with all local associations, we feel there has to be a commitment to helping those with spina bifida far greater than the financial gains the job offers. Frankly, such a salary is an insult to everyone who gives their time and efforts in raising funds for the association.

The Isle of Wight Association is not affiliated to the national group and

this is just one very good reason why we will never consider affiliation, and I hope those people who raise money for the national ASBAH will think twice in future and perhaps direct such funds to the local groups where all their efforts will benefit the handicapped members.

These comments are not in any way meant to criticise the wonderful work which Miss Gilbertson has done for the Association over the past 14 years, and we wish her a very happy retirement.

D J S Sprake, Secretary, IWASBAH

**Patrick Daunt,
Chairman of ASBAH
replies:**

"Mr Sprake has raised an important point of principle but his approach to it is wrong-headed and his conclusion quite mistaken."

The quality of service offered to people with disabilities in this country depends, above all, on successful co-operation between professionals and voluntary workers. But this co-operation in turn depends on a clear-minded perception by all concerned of the difference between the conditions of voluntary and professional service.

The idea that, because there are many voluntary workers active in a given field, professionals working in that field should be paid less than they would earn otherwise is simply muddle-headed and if we applied it the consequences for the quality of our work would be catastrophic.

The executive director of national ASBAH has a major responsibility both in the management of people and of finance, and in the initiation as well as implementation of national policy. Any suggestion that such work should be remunerated at less than its true market value merely downgrades the common endeavour of professionals and voluntary workers at all levels to promote the best possible quality of life for those with spina bifida or hydrocephalus."

Parents with spina bifida

My name is Stephanie Carr and I am a student midwife. I am currently doing a project on pregnancy and early parenthood in women with spina bifida.

If any pregnant women or new parents with spina bifida would be willing to correspond with me about their experiences I would be very grateful and all information thus gathered would remain strictly confidential.

If you'd like to help Stephanie, send your letters to the editor, address on page 3, and we'll pass them on.

Swedish contact

A family in Sweden are looking for a similar family in England with whom they can "exchange experiences and perhaps visit each other". The Johanssons are a family of four - Mrs Johansson is a part-time teacher, her husband is an engineer and they have a daughter Hanna, who is 13, and 9-year-old son, Per, who has spina bifida. The whole family is interested in sport.

You can write to them at: Mor Annas vag 60, S-730 50 Kallered, Sweden.

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

Small adverts for the next issue of Link (December) should be submitted by Friday, 9 November. Please send them to: The Editor, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

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