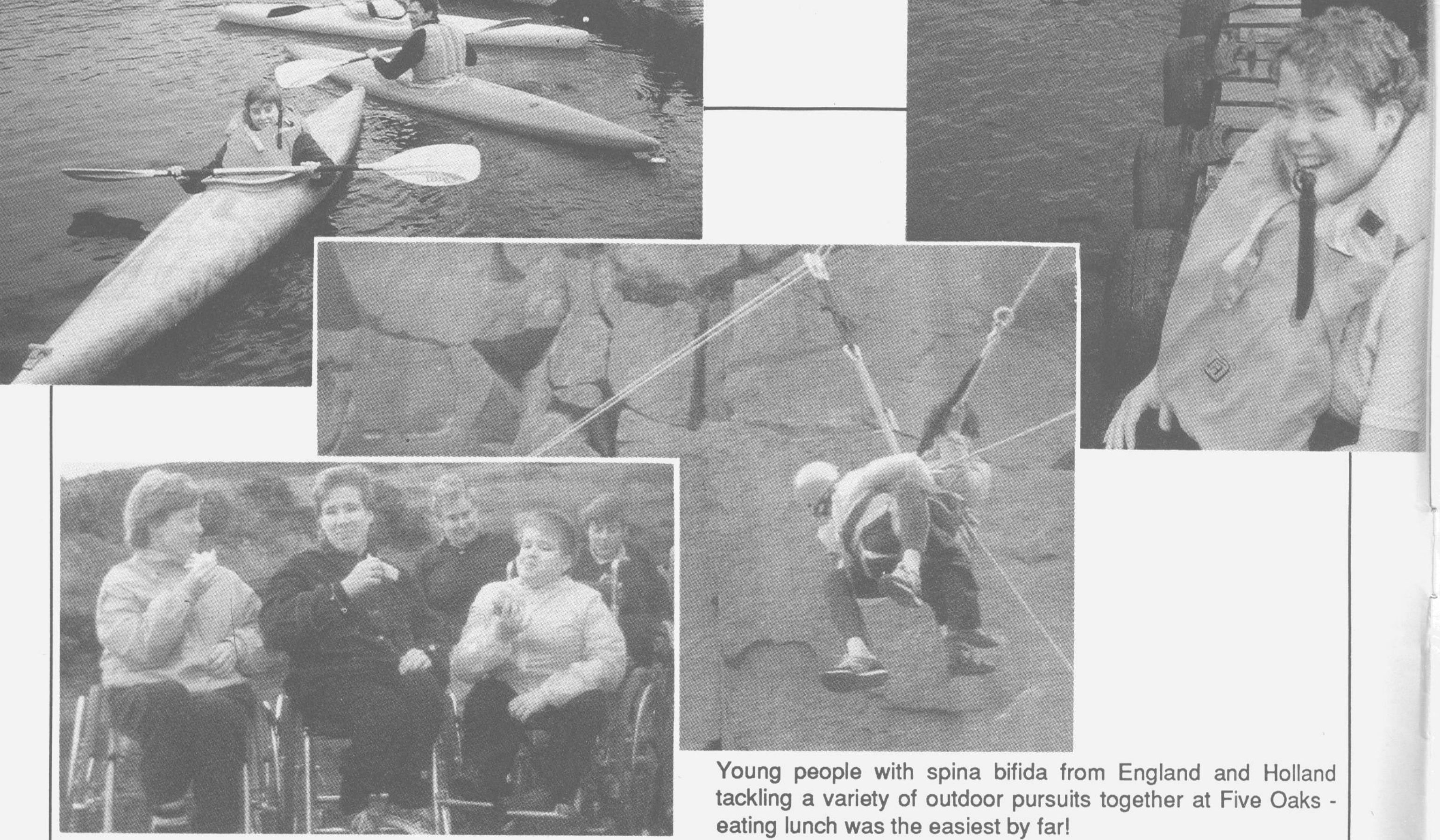
Link

Association for Spina Bifida and Hydrocephalus/ASBAH

September/October 1988 Issue Number 118 30p



Young people with spina bifida from England and Holland tackling a variety of outdoor pursuits together at Five Oaks - eating lunch was the easiest by far!

ANGLO DUTCH ADVENTURE WEEK AT FIVE OAKS

FACING CHALLENGES TOGETHER

A very special Anglo-Dutch outdoor pursuits week took place at Five Oaks in July, and came about because of the close friendship between ASBAH and the spina bifida association in Holland - BOSK

The International Youth Exchange Centre agreed to sponsor a special exchange visit by Dutch members of the association as part of the William and Mary 300th anniversary celebrations this year .

There were five Dutch and four English young people, four English volunteers, Debbie Jackson, course co-ordinator (who is one of Five Oaks' support workers) and Bill, the Five Oaks driver. The young man who together with ASBAH's Executive Director Moyna Gilbertson was responsible for this speedily planned visit, was Peter Meyer whose sister Ariane has spina bifida and whose family are very much involved in the spina bifida association in Holland..Peter was there with his friend, Maria.

The group plunged into the deep end in more ways than one by starting the week on Saturday with canoe practise in a local school swimming pool - it was the start of what turned out to be quite a wet week.

It was time for lazing about, enjoying a pub lunch and swopping English and Dutch songs on Sunday, in preparation for Monday's day 'down under' with many people very doubtful that you could go pot holing in a wheelchair.

They certainly managed it in fine style, helped by a group known as Brad 4. A member of Brad 4 went down the pot with a small trolley with a rope attached, and the person going down was lowered into it . Then they were pulled along the pot and had to control the direction of the trolley with their hands - not as easy as it sounds.

"One of the things none of us expected was that the cave had an underground stream, often a foot deep, with the coldest water I've ever felt. Imagine sitting in that for 20 minutes!" remembered Debbie Jackson, course co-ordinator.

The reward afterwards was a warm swimming pool, jacuzzi and sauna.

In cold, windy conditions the next day the group faced new challenges - this time rock-climbing and abseiling with Brad 4 on the Cow and Calf rocks above Ben Rhydding village.

Wednesday was set aside for shopping. One unfortunate good-looking, long-suffering policeman had his photograph taken with six of the Dutch visitors in turn!

The last day, the sun decided to show its face - just in time for the group to go to Doe park for sailing and canoeing. Back at Five Oaks that evening there was a barbeque laid on by Nigel the chef and goodbyes were said with plenty of wine and song.

"Hopefully this will be the start of an annual event" said Debbie. "A big thankyou to all the volunteers, especially Peter and Maria."

ASBAH news

Just dropped in from New South Wales!

The morning of August 3 started out much as normal, but turned out to be a very memorable one - because of a totally unexpected and very welcome visitor - Professor Bob Zachary - known to so many families in this country and overseas.

He turned up out of the blue at London office - just dropped in from New South Wales!

"It was marvellous to see our Founder Chairman again, and we had a long chat and our conversation ranged around many topics dear to all our hearts" said ASBAH's Executive Director, Moyna Gilbertson. "Professor Zachary has a most retentive memory and asked many questions about individual people and had stories to tell of his own. Although in theory his home is now in Australia, he travels widely and was in the midst of a world-wide tour catching up with his family in England, Nova Scotia and the United States and also visiting friends in Czechoslovakia and Japan.

"We talked about many families and individuals whom he remembers so well. He keeps in touch with us all, particularly via LINK, and I know that he is considering coming to the 1989 meeting of the Society for Research into Hydrocephalus and Spina Bifida at St John's College, Cambridge.

"We all hope that he will visit us again soon, but in the meantime, I am delighted to pass on his greetings to everybody. He is well. He is thinking of you all, and he loves to have your news. So if anyone who knows Professor Zachary would like to send him a message, do please let me know", added Miss Gilbertson.

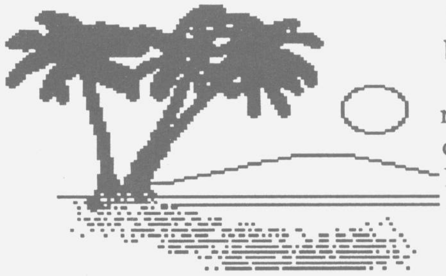
Prof Bob Zachary, at a recent ASBAH event

LINK READERS' HOLIDAY to FLORIDA - Oct/Nov, 1989

A preliminary notice about the holiday was published in LINK May/June issue, so that people who were interested could make a note and start to save!

Since then we have had many phone calls from people who are interested in the holiday and anxious that they may have missed out on further information or the booking form.

Don't worry - you have missed nothing. Panovista's John Brown has just returned from Florida and will soon be finalising the arrangements for the LINK holiday next year, including the price. Full details will be in the next LINK, and you can then send to Panovista for a booking form.



If you are worried in case you don't get the next LINK or it comes very late, why don't you send your name and address to John Brown **now** and ask him to send you the booking form and full details direct when they are available: John Brown, Panovista Travel, 78 Sea Road, Fulwell, Sunderland. (Tel: Sunderland 549 4444).

ASBAH STUDY DAY
for parents and professionals

Saturday October 15, 1988

Royal Shrewsbury Hospital North Educ. Centre.

Subjects to be covered will include hydrocephalus, driving, benefits, employment.

FURTHER DETAILS FROM
Mrs Denise Dunning at ASBAH 's London office.

Conductive Education

Because of lack of information about the relevance of conductive education to young people with spina bifida and/or hydrocephalus, Carole Sobkoviak, an experienced paediatric physiotherapist and member of ASBAH's Medical Advisory Committee, is going out to Hungary in the autumn to look at the Peto Institute and other paediatric services in that country.

Carole and Moyna Gilbertson have been to the new Foundation for Conductive Education in Birmingham run by Andrew Sutton. The trainee conductors are unfamiliar with spina bifida and hydrocephalus and would need to return to Peto for further training before any young people with these disabilities could be included on their courses.

At present the medical profession is unclear about the benefits of conductive education for people with spina bifida and/or hydrocephalus. On the other hand ASBAH has met parents who have returned from Hungary pleased with the progress made by their children.

ASBAH looks forward to Carole's report and meanwhile will continue to keep in touch with, and to monitor, developments in this country.

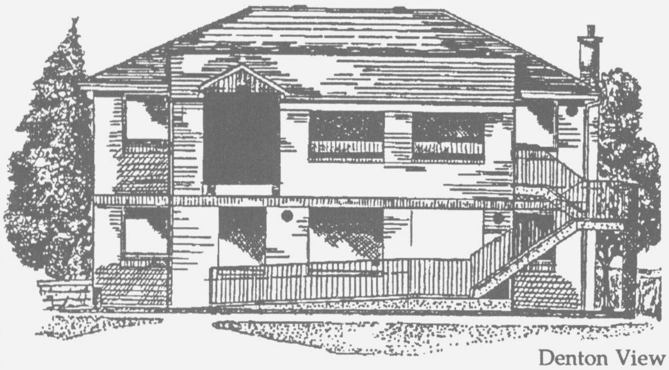
The changing role of Five Oaks

For the past five months residents and staff of Five Oaks residential centre have been subjected to the disturbances caused by builders at work. However, such endurance is about to be rewarded with the completion of a new accommodation project for people with spina bifida and/or hydrocephalus.

ASBAH's new housing project, due to be completed by mid-November 1988, has been developed in partnership with Sanctuary Housing Association Ltd, a national housing association owning more than6,000 homes.

ASBAH first discussed the development possibilities of Five Oaks in 1982, and has since revised many plans and ideas to produce a variety of accommodation which is able to meet the changing housing needs of young physically disabled people.

The project consists of two new buildings: **Denton View** - providing self-contained bedsits with individual training programmes, and **Wharfedale** - a mixture of shared and single accommodation.



Denton View

DENTON VIEW -

ACCOMMODATION AND TRAINING PROGRAMME

Denton View is a two storey block of four self-contained bedsit flats, connected to the main house by a "bridge" which allows wheelchair access to the upper floor. Each bedsit has its own kitchen, bathroom/toilet and living/sleeping area. All the bedsits are furnished and the kitchens are well equipped with height-adjustable cooking and sink units offering a design flexibility to meet individual needs.

The aim of Denton View is to provide young physically disabled people with an opportunity to learn and develop personal and daily living skills within a housing environment which is both supportive and independent.

Each resident follows a training programme geared to their own specific needs and may include training in the management of personal care, household and domestic tasks, budgeting and financial skills. The accommodation and training programme may be provided for single people for an initial period of six months, at the end of which residents are encouraged to consider their future housing needs with the help and advice of ASBAH staff. In most cases ASBAH hope to be able to provide residents of Denton View with move-on accommodation within the Wharfedale complex. However, this may not always be possible or appropriate and residents may be advised on other housing options or extending their period of training at Denton View.

Residents of Denton View receive care and support from the staff at Five Oaks and each bedsit is connected to a 24 hour alarm system.

Denton View is to be registered with the local authority under the 1984 Act as providing residential care, it will therefore be one of a limited number of schemes in Great Britain which offer privacy and autonomy to disabled people receiving full care support, in residential accommodation.

WHARFEDALE -

HOUSING FOR INDEPENDENT LIVING

Wharfedale is a two storey complex of single and shared flats, situated next door to the main house on what used to be the croquet lawn. Like Denton View, the design of each flat offers full wheelchair access and the flexibility to meet individual needs.

The aim of Wharfedale is to provide independent accommodation for physically disabled people within a supportive environment. The complex consists of a three bedroom flat, a two bedroom flat and two one bedroom flats. The one bedroom flats are completely self-contained and furnished with items, such as bed, cooker, fridge,

continued on next page

The changing role of Five Oaks *continued*

curtains etc. The flats are available for either single people or couples. The two and three bedroom flats are for single people to share. Each person has their own bedsitting room but shares the kitchen, living room and bathroom/ toilet with the other inhabitants.

The residents of Wharfedale receive regular day time support which includes help with arranging medical services, statutory services, such as home-help, and advice about welfare benefits and budgeting. Although personal care needs are not met by Five Oaks staff, help and advice is given to residents on how to meet their needs and each flat is linked to a 24 hour alarm system.

Wharfedale

Each resident is awarded a secure tenancy by Sanctuary Housing Association Ltd, making them responsible for the payment of rent, rates and other household expenses. However, staff are on hand to give advice.

Wharfedale offers young disabled adults the opportunity to experience shared living; working as a 'household' with friends and flatmates, an experience which is often denied physically disabled people but usually thoroughly enjoyed by their able-bodied peers. Wharfedale also provides what is often seen as the ultimate aim within the independent living process, that of self-contained accommodation........a home of your own.

Carolyn Smith
ASBAH's Accommodation Officer

If you would like to know more about housing at Five Oaks Residential Centre, please contact Carolyn Smith, ASBAH's Accommodation Officer at the London office.

Reading Matter

Wheelchairs

Published by Oxfordshire Health Authority

This is the sixth edition and incorporates many improvements in wheelchair design and essential details necessary in choosing a wheelchair suitable for one's needs. It is fully illustrated throughout.

Price £4.50 plus £1 p and p. Available from Equipment for the Disabled , Mary Marlborough Lodge, Nuffield Orthopaedic Centre, Headington, Oxford OX3 7LD.

COPE (second edition)

from Wiltshire Careers Service

The second edition of COPE (compendium of post 16 education and training in residential establishments for handicapped young people) is now available.

COPE provides detailed information on residential establishments offering further education and/or training to young people with handicaps or special needs.

A full page of information is provided for the great majority of establishments, including a general description of each college or centre, its stated aims, categories of handicaps accepted, details of courses etc., intake dates, waiting lists and fees, method of application and selection, staffing and care provision, links with local FE colleges and the community.

Price £6.85 per copy inc. p and p. Orders to Wiltshire Careers Service, Support Services Unit, Room 341, County Hall, Trowbridge BA14 8JB. Payment must be included for single copies. Cheques payable to 'Wiltshire County Council'.

ATHLETIC Challenge

'Athletic Challenge' is the first national, full colour, glossy, monthly magazine to promote and cover only sport for sportsmen and women who just happen to have a disability. Issue no. 1 was out in July.

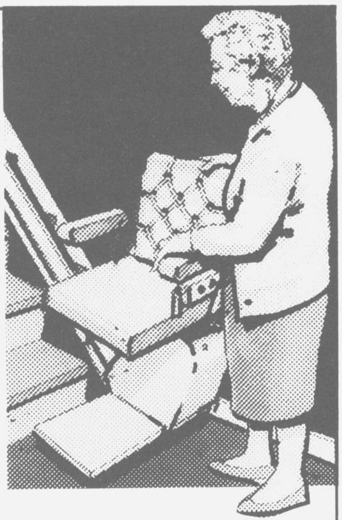
What's of extra interest is that Editor, Josie Cichockyj, is a young woman who has spina bifida. (She has featured in a previous LINK over her disgust that petrol stations were so infrequently accessible for disabled motorists).

'Athletic Challenge' intends to show the true meaning of 'Sport for All', and will give athletes the recognition they deserve for their sporting achievements - something that hasn't been done in the national media before now.

It is available by subscription at £15.60 for a year. The first 2,000 subscribers will receive a free 'Athletic Challenge' t-shirt each.

For your subscription write to Athletic Challenge, 4 Crofthouse Lane, Marsh, Huddersfield, HD1 4NX, enclosing a cheque/ postal order payable to 'Athletic Challenge'.

GIVE YOUR LIFE A LIFT



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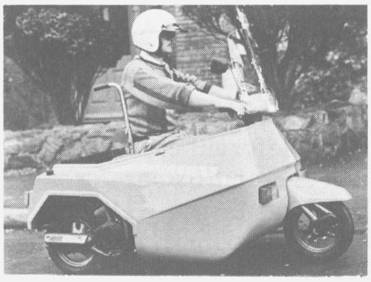

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My child is going to be assessed... what does it all mean?

by
Albert Reid
Senior Specialist
Educational
Psychologist
for ILEA

The term 'assessment' can conjure up visions of mental obstacle races dreamed up to further impede children already at a disadvantage.

The old ghost of the 11 plus with which many of us grew up has added to this mythology, particularly as far as psychological assessment is concerned . There is the deeply entrenched view that you either pass or fail this kind of assessment. We all feel at a disadvantage when we don't have a clear idea of what is being asked for, how information is being gathered and what weight will be given to the various parts of the picture that emerge.

Current attempts to involve parents in the process of assessment and to make this process itself much more understandable go against not only these prejudices, but also ask a great deal of parents, children and professionals in rethinking the way we see each other and the roles we naturally and perhaps unhelpfully fall into.

The last fifteen years have seen quite a profound shift in the way in which children with conditions like spina bifida and hydrocephalus are seen educationally. Many parents will be aware of the trend away from special schools and segregation, a move which also now tries to acknowledge not just the handicaps - those aspects of a child which slow down their development - but which seeks to place in a much more prominent place those qualities and skills that children may have. These include aspects of a child's personality, such as motivation, which have a very real effect on learning.

The term **'special educational needs'** is now frequently used and intended to convey as complete a view of a child's abilities as possible, not only to register, for example, the need for a wheelchair, but also to draw attention perhaps to an ear for music or a pleasant personality.

Inevitably this view of an individual child's needs requires comprehensive assessment, recognising that the classroom is not the only place in which he or she exists; that classroom-based assessment allows one fact to be explored, but a sense of perspective requires knowledge, too, of the child at home and at play.

This means that parents' views of how their children learn, cope socially, how well they make friends, and how independent they are becoming, are important contributions to any meaningful assessment.

These views need to be fitted into a **multi-disciplinary framework,** to note another current phrase. Children and young people with spina bifida and/or hydrocephalus will have a range of needs to be met involving, at times, paediatricians, physiotherapists, occupational therapists, educationalists and so on, and it is important that a balanced view, in educational terms, can be maintained, with information shared between professionals and family to enrich comprehensively what is on offer.

All of these views must make sense to parents and children. Discrepancies must be looked at and plans made on the basis of **all** the information, like pieces in a jigsaw, which only when assembled, allow the complete picture to be seen.

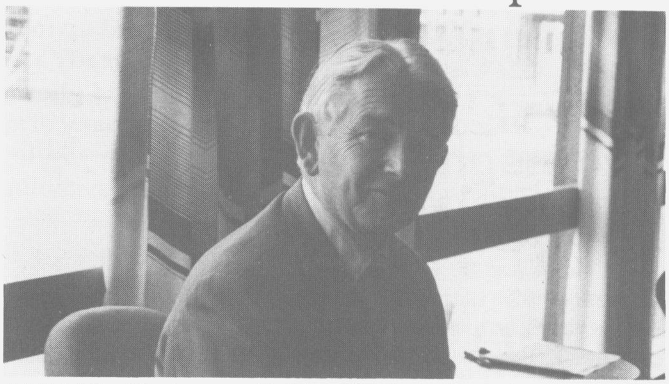
This is particularly the case at the time a child's Statement of Special Educational need is drawn up and the 1981 Education Act has placed much more emphasis on parents' rights and the multi-disciplinary nature of the assessment than previously was the case. Parents' views are initially sought. They have the right to appeal if they feel a Statement does not adequately outline their child's needs and they are entitled to view the reports professionals have contributed and discuss these with them if necessary.

The reassessment at about 13 years under the 1981 Act is another focal point - a time when plans can be made involving the young person, taking into account again skills, with particular emphasis on independence and mobility. It is important at this point to seek advice from careers advisers and, in some cases, from social services. The purpose of this reassessment is to share views with parents and the young person again about what his or her needs continue to be, to amend the Statement and use this as a continuing basis to review the provisions made.

The emphasis is upon communication, a sharing of views and a continuing dialogue about not only current progress but also plans about the future.

ASBAH Conference, September 2 - 4, 1988. Southampton

"Children with spina bifida/ hydrocephalus - grown up"



ASBAH's Chairman, Robin Mackenzie at the conference

Two important needs made themselves apparent throughout the conference - the need for independence for young people with spina bifida and/or hydrocephalus and the need for ASBAH to give more attention to training and counselling said ASBAH's Chairman, Robin Mackenzie in summing up the weekend.

The conference made it clear that independence meant not only of bodily care but also an independence of spirit, and the ability to make relationships outside the home. Mr Mackenzie emphasised the importance of being realistic when assessing the potential of any individual. He said that the association realised that **training** was now one of the priorities in view of the changing needs of young people. This included training for parents, for government departments, local authority departments, and also for employers.

ASBAH's Executive Director, Moyna Gilbertson, said that there was also a need for ASBAH to train **more counsellors**, The conference had highlighted, too, the members' wish that ASBAH should play an even greater role in **lobbying** government and authority. In order for ASBAH to have the ammunition to lobby strongly and effectively it needed to know exactly what was happening at grassroots level. There was a need, said Miss Gilbertson, for much greater communication between those with spina bifida and/or hydrocephalus and ASBAH. "We can't lobby or fight for you if we don't know what you want."

She agreed that ASBAH should try and find a way of sending back more **information** to local associations on subjects such as benefits, grants, housing etc.

Discussion during the weekend brought to the fore the lack of motivation and dependence of many **young people,** and the need to find the best way of helping them to achieve their potential and lead as full a life as they wished. ASBAH has set up a working party to review the work of young ASBAH -'LIFT' -and to see how it can best find out what young people want and meet these needs. The inability of many young people with spina bifida and/or hydrocephalus to stir themselves into action led the conference to consider the important role that could be played by 'a trigger' person. ('trigger' became one of the favourite conference words!). A 'trigger' is someone - definitely not a parent or main key worker - perhaps a friend, who, as the name implies, could 'trigger' the young person into action whether it be into joining a particular local club, or putting their name on the housing list, or to remind them to pay their rent, or 'to trigger' other people to provide facilities or employment or other kind of help.

The conference, held at Southampton University, was attended by members of ASBAH - including a welcome number of young members - and professionals from all round the country who not only had time to debate important subjects in workshop sessions but to listen to a number of speakers whose talks are summarised below and on the next three pages in the order that they occurred.

* * *

PROBLEMS OF AND PROVISION FOR YOUNG ADULTS

Nancy Robertson, Director, Prince of Wales Advisory Group on Disability

Mrs Robertson's main theme was the need for young people to be responsible themselves for finding out what was available. Many problems arose, she said, from young people being too dependent on their families. It might be painful, but it was necessary to 'cut the umbilical cord'.

Mrs Robertson said that the first step to independence often happened when the young person went away for the first time, perhaps on a course or on holiday.

It was essential for young people to take responsibility for their own personal needs.

Provision within the community varied enormously from region to region, she agreed, but felt that there was great benefit to be derived from joining something like a PHAB club, a local DIAL group, or even going to a day centre.

Mrs Robertson felt that nowadays there was a more forthcoming attitude from the public towards disability. "We should be willing to go half way to meet that kind of approach. There is still, however, a long way to go."

She said that having a disability was undoubtedly a 'big burden' with many difficulties to face such as health, housing, jobs etc. but "there is a lot going on. Get out and find out about it."

continued on next page

asbah conference.....2

OPPORTUNITIES IN FURTHER EDUCATION

Richard Stowell, Director, National Bureau for Handicapped Students

There were few disabled students in higher education or at university - about 500 out of over 100,000 students. Most needed time to catch up, and further education at a local college or a special residential college was one way of doing this. Mr Stowell felt that the declining school population over the next ten years could possibly lead to more college places for disabled people in the future.

Vocational training leading directly to a job was another option open to disabled people, but increasingly pre-vocational training was becoming the most popular avenue and had been greatly improved, after the dramatic increase in youth unemployment in recent years. This had brought many more disabled students into local colleges where they could learn basic skills and catch up on general education and literacy. Ten years ago there were no more than 3,000 disabled students on pre-vocational courses. This had increased to more than 55,000.

For the less able student with learning difficulties there were special courses available. There were about 136 such courses on offer around the country (approx. 1 in 3 colleges). He referred to a directory of colleges*

Mr Stowell did not, in general, favour the other option - staying on at school up to the age of 19. "It is better to get out into a challenging environment".

Initial training (pre Youth Training Scheme) and YTS itself offered good opportunities he said. He emphasised the importance of not only training for work, but also for leisure - a very real option for life.

With reference to the Education Reform Bill, Mr Stowell called for local associations and other local disability groups to pressurise their local education authorities to make sure that they did provide sufficient and suitable educational opportunities for everyone. The Act made it **a duty** of the local education authority to provide education for **all** young people to age 19, but that duty had to be translated into action. He felt that pressure in other countries like the USA, had led to good provision for students with disabilities. During discussion, concern was expressed at the attitudes that might be taken by the new governing bodies of schools which would be looking at budgets and trying to attract the maximum number of pupils . They might feel that disabled pupils would increase costs and could bring down the overall examination results. On the other hand, said Mr Stowell, if a fuss were made by a local disability group like ASBAH about lack of provision in a particular school, it could damage the reputation and standing of the school in the community. It was vital for the future education of young disabled people to "get out and demand your rights".

**COPE (Compendium of Post 16 Education and Training in Residential Establishments for handicapped young people), price £6.85 inc. p & p from Wiltshire Careers Service, County Careers Centre, County hall Annexe, Bythesea Road, Trowbridge, Wilts. BA14 8EZ.*

HOUSING PROVISION

Charles Moore, Director, John Grooms Association for the Disabled

Although the picture was largely dismal and provision very patchy, there was still hope. It was absolutely vital for disabled people and organisations to make their needs known locally. They should start by getting their names on the housing list. This was the only way in which needs become apparent and this could then be translated into action.

It was an obstacle course, and one of the problems was the lack of experience of many disabled young people in dealing with authority. Parents must let their children go so they could start to experience how to stand up for themselves at an early age.

Mr Moore estimated that 50% of people at present in residential care could live in normal housing if the opportunity were available. Young people often needed to learn in advance the responsibilities of having a place of their own, ie. the need to pay regular rent.

He said the major need at the moment was the lack of housing with care facilities. A lot of young people with spina bifida/hydrocephalus could live independently or in a group if they had a 'trigger' carer - someone like a friend to remind them to pay their rent, to plan ahead etc. He referred to two John Grooms' housing initiatives - in South End and Norfolk - providing 'negotiated care' for young people who really were determined to be independent. Care was provided for two years. One essential was they had to be on the housing list first. It was no good going home to mum and dad afterwards and wasting all the training.

During a housing workshop later in the weekend Mr Moore spoke again of the importance of establishing the need for housing as soon as possible. Overall in the country, there were more wheelchair units available than takers - although the actual shortfall on paper was 7,500. This was because they had been built in the wrong places where no-one wanted them - i.e. in the middle of a development for the elderly, or without care provision.

He said John Grooms had been asked by four housing authorities to clear disabled people out of their geriatric wards and had been given £9 million to do this.

He also spoke of the importance of registering a home. It could be registered if providing care for more than three people. This registration unlocked benefits, such as £195 a week for care. He recommended a useful book on the subject: *The Registered Homes Act Guide, Nation Federation of Housing Assns., 175 Grays Inn Road, WC1X 8UP.(Tel: 01 278 6571.) Price £6.50 to include p and p.*

Another suggestion of his was the possibility of a local association negotiating with a building society for a mortgage for a home on the basis of paying back only the interest and not the capital sum.

Local ASBAHs should get in touch with all the housing associations in their area to let them know what their needs were or were likely to be.

"You have to work hard at it, but there is great scope if you can get your act together".

continued on next page

Enjoying the sunshine outside the lecture room at Southampton University

TOWARDS EMPLOYMENT

Jane Pitcher, Special Needs Advisor, ILEA Careers Service

Ms Pitcher, describing the work of the ILEA, said that there were 14 Special Needs Careers Officers. A recent survey in London looking at where disabled school leavers went immediately after leaving school had shown that nearly half stayed in education after the 5th year, 10% found work (usually the less disabled), and 15% went into YTS - a larger group thanfor work and unemployment together.

The pattern for disabled school leavers was totally different then for those who were able-bodied. They needed longer time in which to settle and this could lead to frustration. It was achievement that mattered at the end of the day, not age.

Ms Pitcher spoke about the quota system which had 'no teeth'. Employers needed to be told of the positive aspects of employing a disabled person. She considered that staying on at school was only beneficial if a totally new course was offered to stimulate the young person. In ILEA those with moderate learning difficulties were not kept at school because of the good further education provision.

There was a long waiting list for residential further education and it was, therefore, necessary to plan far ahead. Financial stringency was also becoming a problem.

Referring again to YTS, she said not enough young disabled people were aware it had been extended for them to age 22. Too few disabled young people were in YTS schemes that were job-orientated or which led into jobs.

Employers, in her opinion, were often reluctant to take on people with disabilities because of fear and lack of knowledge. It could be helpful to involve them in other ways, such as helping with careers programmes in special schools, giving mock interviews. Through this kind of contact with disabled people, their fears might be dispelled.

PERSONAL LIFESTYLE PACKAGES

Len Gale, Specialist Careers Officer, Hereford & Worcester

The main thinking behind the Herefordshire Lifstyle Project of which Mr Gale spoke, was the need for disabled young people to have control over what they did in life instead of accepting what was given. The project started in 1984 with Alison, badly injured in a road accident, who left the Star Centre clearly too disabled for employment and didn't want to spend her time with geriatric people in a local day centre. Mr Gale decided **to ask her** to work out how she'd like to spend her time. It wasn't easy for her to do but eventually she came up with a package that included physio, speech and hydro therapy, some further education, a little time at a day centre and half a day work experience. Over the years the package has changed with greater emphasis on further education and now on work.

Another package was then devised for someone else and in September 1985 a one year pilot scheme was started for ten people of all ages and disabilities with unmet needs. Four of the people said their lives had begun to change for the better, four had small, but significant changes, and the other two got little out of it.

Just when it was thought that the scheme couldn't expand further, the Spastics Society came in as co-ordinator, and now work is proceeding to develop packages for up to 50 people.

Explaining the scheme's structure Mr Gale explained that each person chose their own 'key worker' - perhaps a friend (certainly not a parent or principle professional worker). The key worker kept an eye on the scheme's progress and some times might have to push to get what was needed. The scheme, though it didn't just work like magic, gave young people a much greater say in their own futures, and had had the effect of breaking down barriers between professional workers and departments so they talked to each other, and also had identified gaps in provision such as accommodation and transport.

Future plans were to look at lifestyle packages with regard to the transition from school, and a rehabilitation package. Lifestyle offered much greater flexibility, he said, than building a whole new, expensive rehabilitation centre.

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INDEPENDENT LIVING

Peter Swain, Co-ordinator, Exeter Council for Independent Living

Mr Swain gave a talk and slide presentation on a recent visit to Scandinavia to look at their services for disabled people. ASBAH was one of several organisations which had helped to fund his visit.

The study had shown a high quality of services in Scandinava generally. Finland perhaps was slightly less well served than the other countries, but the situation there was improving.

continued on next page

asbah conference...4

Provision for disabled people in Scandinavia had also been a State responsibility and facilities and services were of a very high quality and usually free. Disabled people weren't regarded as special but were linked into the rest of society. A consumer poll two years ago produced a 100% response from the 270 municipalities. 10% were shown not to be providing a good, widespread service and the government immediately looked into this.

ASBAH members were amazed at the high quality and availability of facilities, services and equipment, and the freedom and independence these had given disabled people in Scandinavia. It was recognised that the population of the Scandinavian countries as a whole is much lower (8.5 million in Sweden) but nevertheless it was an eye-opener into the standard and quality of life that people with disabilities could be helped to enjoy, given the right climate of opinion, the determination and the resources.

Denise Dunning, ASBAH's Education, Training and Employment Co-ordinator leading one of the workshops

COPING WITH PERSONAL CARE

Clare Michelmore and Ian Laker of the Disabled Living Advisory Services Department of ASBAH.

Too many people were afraid to change systems. It could be quite a good idea to look around and see if anything else on offer would be more convenient. Don't be afraid to change. Your doctor will change the prescription. You are not duty bound to stay with your original choice.

Most major suppliers offered a freephone incontinence advisory service and quite a few of these did advise other systems than their own if they felt them to be more suitable.

Some suppliers, e.g. Thackray, have nurses who will go to individual homes. Competition was increasing in the incontinence market and suppliers were anxious to please.

Any problems with getting supplies through on prescription should be referred to the Community Health Council.

Clare Michelmore made the point that nothing could beat good old soap and water and general good health care management. It was essential to have a good routine and change appliances regularly.

They both touched on different surgical methods to achieve continence, such as artificial sphincters, undiversions, bladder replacement and nerve stimulation . LINK hopes to invite leading experts on the subjects to write in some detail in future issues.

RELATIONSHIPS

Pat Edser, Fieldworker, ASBAH

There was so much interest shown in the talk on relationships by Pat Edser that it has been agreed to publish it more-or-less in full in the next LINK instead of merely summarising it this time.

She looked at the problems many young people with spina bifida and/or hydrocephalus have in forming friendships and sexual relationships.

It is obviously a subject that is causing concern to many families. Pat Edser is not only one of ASBAH's fieldworkers but has also had training as a counsellor and spends quite a lot of her time talking to young people and trying to help them to come to terms with their sexuality and need for friendships.

Listening intently to one of several workshops held at the conference to discuss subjects such as personal relationships, housing, mobility.

COMPUTER STUDIES

We have heard from North Wales Association who are purchasing computer equipment with £2,000 given to them from the BBC Children in Need Appeal.

"It occurred to us that other associations may be trying to introduce disabled members to computer studies and, if so, perhaps we could swop ideas, and later, experience. Could any other associations who are involved please get in touch" says Mrs Joan Bee, Chairman, N. Wales ASBAH. Her address is: Tan y Marian, The Dingle, Penmaenmawr, Gwyned, LL34 6BA. Tel: 0492 623433.

The year's achievements

Summary of the annual review by ASBAH's Executive Director, Miss Moyna Gilbertson.

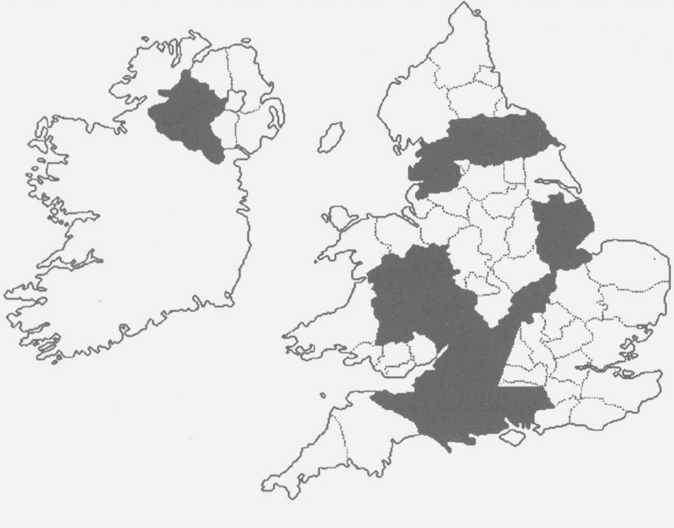
The past 12 months had not only been busy because of ASBAH's expansion of services, but also because of the work involved in planning for the future, said Executive Director, Moyna Gilbertson in her summary of the year's activities to the Annual Meeting.

The decision to move to Peterborough came about after a feasibility study which highlighted the need for more space to accommodate the lucrative and growing telesales department and in order to expand services even further.

The estimated bill of about £60,000 for a much-needed lift at the present office premises in Upper Wo-burn Place was 'the last straw' in a saga of soaring costs said Miss Gilbertson. The thought of being in new, fully accessible offices was very encouraging.

Expansion of fieldwork

Miss Gilbertson expressed satisfaction that the fieldwork service had been expanded during the year and there were now fewer 'black areas' (see map below), not covered by ASBAH fieldworkers. Expansion of the service continues and this Autumn a new fieldworker was to be appointed to cover Fermanagh and County Tyrone. During the last few months, when emergency cover had been provided here by the Northern Ireland fieldworkers, 300 families had been referred, said Miss Gilbertson, and it was anticipated that this would soon double. Fieldworkers had a heavy case load - 150 families on average and in some cases as many as 300. Some agencies considered 20 active families quite enough for one worker.



Areas not covered by fieldworkers are in black

Videos and publications

The need for good audio visual material had been recognised and a video on spina bifida in relation to the school years was being made with funding from the DHSS and SEAT cars. ASBAH was also cooperating with Birmingham Children's Hospital to produce a video on intermittent catheterisation thanks to help from Dorothy Artingstall of Midland ASBAH. A new Guide to Services, entirely funded by telesale advertising, had been well received and distributed to social services department, health authorities and interested professionals. Publications in general continued to be in demand and 'Spina Bifida and You' had been translated into Dutch.

Housing options

ASBAH's Accommodation Advisory Service provided by Carolyn Smith had been in ever increasing demand. During the year ASBAH had been asked by a well-known children's hospital to advise on accessible toilets. Links with Stackpole Trust, Living Options, and the London Hotel for the Disabled had continued during the year.

The exciting news of the year on the housing front said Miss Gilbertson was the developments at Five Oaks where a centre of excellence was developing, helping people with spina bifida and/or hydrocephalus towards self care (see report on pages 6 and 7).

Five Oaks Bursary

A Bursary Fund had been established, and from January it would consider applications from young people needing financial help to go on course at Five Oaks or elsewhere. Donations large and small would be welcomed to keep the fund in a healthy and active state. Details would be circulated soon to local associations, said Miss Gilbertson.

Sponsorship

ASBAH had received sponsorship for two Five Oaks courses said Miss Gilbertson. An Anglo-Dutch outdoor pursuits course had been financed by the William & Mary Tercententary Trust and an International Fashion Course to be held this Autumn was being sponsored by the EEC and Royal Jubilee Trust.

Study Days

Organised by Denise Dunning, Education, Training & Employment Co-ordinator, ASBAH Study Days during the year had proved popular. The Hydrocephalus Support Group Family Days, the responsibility of Disabled Living Advisor, Phillip Watson, had now demonstrated that there was a real need for this special group. ASBAH was getting to know an increasing number of individuals and families coping with hydrocephalus without spina bifida and needing the support of the group.

Assessing LIFT

Miss Gilbertson said that a re-assessment of young ASBAH - LIFT - was in progress and a working party chaired by Austin Crowther of the Executive Committee and with members from outside youth organisations had been set up to look at future developments.

Gathering information

A survey into antenatal services by ASBAH had prompted a gratifying response from over 90 health authorities who sent in very detailed replies. This would help ASBAH answer, more efficiently, the many enquiries received by the Disabled Living Department and especially by Clare Michelmore. All the information had been put on computer.

continued on next page

Careful stewardship

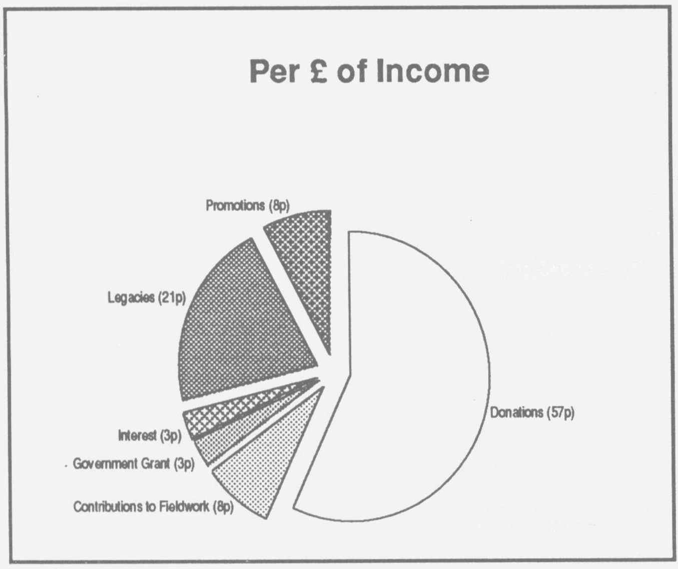
The secret of the relative health of ASBAH's finances was careful stewardship by the Association, said the Honorary Treasurer, Mr A. K. Stewart-Roberts in his report to the annual meeting . Although the Association had been able to expand services and still break even, the situation needed constant attention.

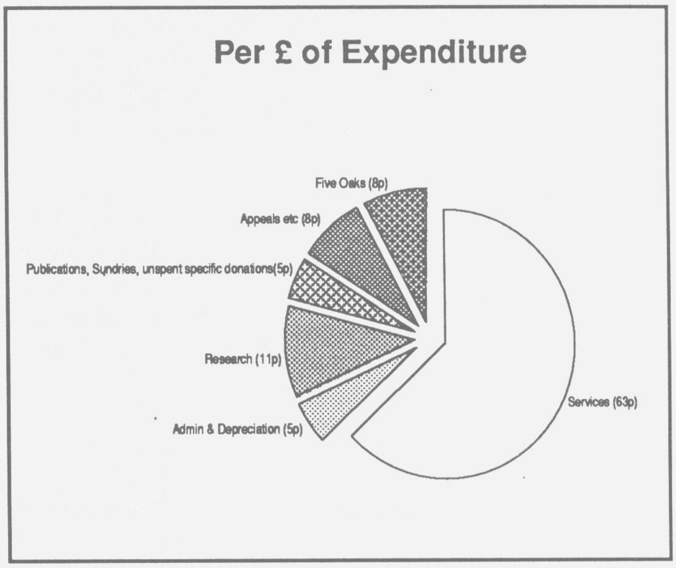
He praised the work of the telesales department which had produced 34% of ASBAH's income.

There had been an encouraging co-operation with local associations which he hoped would benefit fundraising.

The small amount spent on administration -5% - was an indication, said Mr Stewart-Roberts, of the professional nature of ASBAH .

He concluded by saying that the paramount need was to maintain ASBAH's reputation in order to continue to attract donations.


Per £ of Income


Per £ of Expenditure

Gathering information

ASBAH's information retrieval project being undertaken by Pat Corns, Research Officer, had made an encouraging start.

Overseas links

On the world front, Miss Gilbertson said that ASBAH's involvement with the International Federation for Hydrocephalus and Spina Bifida was continuing.

Recent changes within the EEC had led to a recommendation that international organisations (like the International Federation) should have an identifiable European component. In line with this it was hoped that a new European Association would be finally inaugurated at a meeting to be held in Edinburgh later in September.

Research Society

She spoke of the honour of becoming the new President of the Society for Research into Hydrocephalus and Spina Bifida (announced in the last LINK) and said it was a recognition of the strength of ASBAH as a whole.

Changes in the law

Miss Gilbertson made it clear that repercussions from the recent social security changes were being felt by families, and ASBAH was working hard to give appropriate help. It had been a stressful year, particularly in relation to parliamentary matters, and she thanked ASBAH staff for their industry, patience, perseverance and good humour. She also expressed ASBAH's gratitude to committee members, outside advisers and professionals for all their help during the year.

The Annual Meeting paid tribute to the work of Mrs Yvonne Cox as a member of Executive, Chairman of Services Committee and as Chairman of Five Oaks committee. She has retired owing to ill health and will be greatly missed.

Dennis Paul, Vice Chairman of ASBAH has ttemporarily taken over the Chair of the Services Commitee. Dr Gillian Hunt and Mr S Wroe retired and did not stand for re-election. There were no nominations for these positions so they remain vacant. The Executive will, as necessary, co-opt members during the year.

COPIES OF THE FULL ANNUAL REPORT AND REVIEW AND OF THE AUDITED ACCOUNTS ARE AVAILABLE FROM NATIONAL OFFICE.

Shortage of space

We apologise that owing to shortage of space in this issue it has not been possible, as planned, to carry the article about the Exeter Project and development of services for young adults in Devon.

We hope to publish it next time.

Would you like to go on 'Blankety Blank'?

and for Jackie Doughton of Wolverhampton that call from the BBC was the start of a weekend that she will never forget...
Jackie had applied weeks before to take part in 'Blankety, Blank' and had a follow-up interview. Weeks passed and she thought that she had been turned down until that memorable call.
What followed is recalled by Jackie in a letter to LINK........

We stayed in London for the weekend, courtesy of the BBC, at the London Tara Hotel in Kensington*; it was a truly marvellous place with access everywhere - totally suitable for me and my wheelchair....it was perfect and it seemed like I was in on the beginning of a fantastic dream!

The show was recorded on the Sunday at TV Centre and we were collected by the BBC people at noon...they were terrific and looked after all of us contestants throughout the day. Mom was allowed to accompany me to TV centre and so be there if I needed any help..

After lunch we finally went down into the recording studio used for 'Blankety Blank'....we also met Les Dawson for the first time, and he's really so very funny! Les was great, taking charge of me and my wheelchair and, of course, joking all the time. You can imagine! The first thing to decide was what we were all wearing. We had had to bring a couple of different outfits with us for the production team to choose from - "nothing pink or too dark or too 'busy'" were our guidelines.

Fortunately, TV centre was eay to negotiate with my wheelchair - being level and with lifts. The actual set used for'Blankety Blank' did have two steps but this had been overcome by building two ramps, and with a bit of careful steering the whole thing was quite simple to get on to and off. We rehearsed for a while, with BBC staff standing in for the celebrities who were to arrive later. It was amazingly nerve-racking even doing the rehearsal - what with all the people and cameras and lights. Goodness knows what the real thing was going to be like, I thought to myself as we then went up to hospitality (or hostility as Wogan calls it!) for a cup of tea. Afterwards we went into make-up and had our faces made up and our hair done. That was a great treat and made you feel like a 'star'.

The time that day went extremely fast and before we knew it, the celebrities for the show had started to arrive...and the time had finally come for us contestants to get changed and ready to record the show. After putting on our TV clothes, we then went back up into hospitality for drinks - to help calm us down I suspect! We began making our way down to the recording studio -it was really funny because one of us happened to glimpse through a window the people actually queuing to get in to see that night's 'Blankety Blank' - they were waiting to see us....!


Jackie with her 'Blankety Blank' cheque book and pen

The studio by now was absolute chaos. Slowly the audience was coming in and taking their places...and then at 7 o clock the first show got underway, and that was mine, and I was the very first contestant - off I went.

My opponent, Vic, and I sat in our places behind those 'desks' and we soon heard the familiar sound of the "Blankety Blank" music. When the podium began to turn round we could both see the audience, the cameras, the technicians and those terrifically strong lights they have on stages.

We had been told to wave to everyone as we appeared from behind the set and so as soon as everyone and everything came into sight we both started waving like mad - and just in case we happened to forget the floor manager, Duncan, was busy waving back.

Les Dawson made his entrance, cracking jokes as usual. He introduced the celebrities who on 'my' show were Vince Hill, Claire Rayner**, 'Bungalow' Bill Wiggins (who is absolutely gorgeous and from whom I managed to steal a kiss) Linda Lusardi, Mike Reid (from East Enders) and Blue Peter's Caron Keating. Les then walked over to me and started to read out the humorous details about me which he had written down.....laugh a minute is our Les.

Then came my first question, which I well and truly fluffed, and managed to score a 'huge' nothing. "What a good start " said Les. The 'bloke' I was playing against managed to get five with his question and although I manged to get three points with my next, it was no match when Vic answered his second question well and got more points. So it was curtains for me.

More jokes from Les; wave goodbye and that was it. At least I came off stage knowing that I had won my 'Blankety Blank' cheque book and pen and that it had all been such fun and such an experience.

Continued on next page

Blankety Blank...continued from previous page

I sat through the remainder of my show....when recording had finished and everyone had unwound and the audience left...we all went back up to hospitality - contestants, their relatives, celebrities, technicians - everyone, for drinks, eats and generally to unwind after the hectic but very exciting day. It was a real treat being able to chat to people you only normally see on TV. It was great!....

Apparently it was quite unusual for a disabled person to appear on a TV game show and when it had been finalised for me to appear on Blankety Blank another BBC programme called 'One in Four' which is a news type programme made specially for the disabled viewer, had become interested and had asked if before going back home I would do an interview for them about me being on the show...knowing me, I said yes ....the interview went very quickly, with me having to answer questions about being on 'Blankety Blank' and then I was filmed coming to the entrance of the hotel and generally moving about my room...I felt so silly brushing my hair whilst a camera was burring away. Still, it all went to make a day. Before long our car came to pick us up and take us to Euston - a chauffeur-driven Mercedes, no less...

I think my edition of 'Blankety Blank' will be broadcast either in October or November with the new series actually beginning in September. The 'One in Four' programme will go out just before.

If anyone else in ASBAH would like to have a go at a game show then do try because if you are selected you have a marvellous time. Everything is taken care of. You meet great people and enjoyment is the name of the game. Have a go. I had a weekend I will never forget!

**** There was mention of the Tara in the last LINK (p.18)***
***** Claire is, of course, one of ASBAH's Vice-Presidents***

Running for ASBAH .. (above) Mick Mee, Scout treasurer for the 48th Chantry Ryhill cub pack and scout troop, near Barnsley, with daughter Katy and Richard Cook, a venture scout.

They were just three runners in a fun run organised for Barnsley ASBAH by the cubs and scouts in June. Taits motor company of Hemsworth donated £100 sponsorship for them to buy medals and trophies for the runners.

Altogether 150 runners took part in the 5 mile run around the village and raised £265.

Bathtime

Jamie Gilham and Ian Laker, Disabled Living Advisors for ASBAH take a dive into the subject of BATH EQUIPMENT

This short article is intended only as a guide as there are a great number of different aids available. When choosing any aid, a realistic appraisal of your own abilities and needs is the first and best step to take. Some people will require as little as a grab rail, others will need lifts and hoists or even assistance from another person.

There are a large number of manufacturers supplying specialist baths and equipment but their products do fall into particular categories. The categories we use are:
external hoists,
internal lifts, side opening baths and floor level cubicles.

(a) *External hoists*

are a permanent or removable unit, sited near to the bath, that can aid in the transfer of a person from a seat or wheelchair directly into the bath. These hoists can either be powered or manually operated and can be used by the individual themselves or with the aid of a helper.

(b) *Internal lifts*

are either platforms or seats situated inside the bath. They can be portable or permanent fixtures that can be powered either by hydraulics, mains water pressure or even by battery/electric power. This type of aid means that the user must be able to transfer onto the seat either with or without help.

(c) *Side opening baths*

with hinged panels that allow easy access and exit. As with (b) you need to be able to transfer into the bath with or without help. Adjustable height baths exist also.

(d) *Floor level cubicles*

as the title suggests, are cubicles that allow the user to walk/wheel through its doorways to enable a much shorter and more direct transfer i.e. no climbing or clambering over wet or smooth surfaces.

There are obviously more alternatives, especially if you prefer showers to baths.

There are a great many hoists on the market. This is *The Victor* from Victor Hoists Ltd, The Willows, Wincham, Northwich, Cheshire. Tel: 056 589 3860

For further information contact the Disabled Living Dept. at ASBAH, or ring the Disabled Living Foundation (01-289 6111) for the address of a centre near you where you can see the equipment

The side-opening *Parker Bath* makes getting in and out from a wheelchair easy. With the bath pre-filled and in the upright position the bather gets in and the watertight door is closed. The bath is then reclined from within by the bather and water flows from the footwell and around the body. When bathing is completed, a release valve will return the bath gently to the upright position. The bath is made by Parker Bath Developments of Queensway, Stem Lane, Industrial Estate, New Milton, Hants BH25 5NN. Tel: 0425 617598

NEWSLINES

• **Although general entitlement to Income Support has been withdrawn from young people aged 16 and 17 as from September 12 this year, there are some groups who may still qualify for the support.**

Young people of that age who do not have to be available for work as a condition of receiving Income Support will continue to qualify, without any time limit on their entitlement, provided they come into one of several categories, and that includes **those who are severely disabled or the long-term sick.**

A second group of people may also be able to qualify for a limited period, on condition that they are looking for a job or a YTS place. This includes people **who have no parents, people who have good reason for living away from home, and married couples.**

• The amendment to the Local Government Finance Bill to help disabled people on low incomes has been overturned by the Government in the Commons.

The amendment sought to allow disabled people on low incomes or benefits to receive the difference between 20% of the average charge and 20% of the local charge. It was defeated by 98 votes.

The Secretary of State argued that local accountability had to be maintained in every case, and that this amendment was against the very principle of the Bill.

• A select committee of the House of Lords has published a report on the role the European Community plays in promoting the integration of people with disabilities. The report supports the aims of the various action programmes initiated by the Community although it was felt that some of the local projects had been difficult to evaluate. The Committee thought that more publicity should be given to the work of the Community, and that efforts should be made to protect and promote the important contribution of volunteers in assisting disabled people to live independently. The role of non-governmental organisations and experts should be strengthened in planning and implementing future Community initiatives.

The House of Lords' Select Commitee Report on the European Communities on Integration of Disabled People (Session 1987/88, 13th Report) is available from HMSO, price £12.

• It appears that the Office of Population Censuses and Surveys (OPCS) has discovered that there are far more disabled people than previously thought. Rumour has it that the OPCS survey estimates the number to be six million - twice the Government's previous estimate. The first part of the report is due in September, and the second in November, with three further reports during the first six months of 1989.

The Government will have to face the financial implications of the large number of people with disabilities hitherto 'undiscovered' which this report has brought to the forefront. The new Department of Social Security will be faced with having to find major new resources from the Treasury.

• The Department of Social Security is looking for people to take part in a survey of wheelchair cushions. It wants wheelchair users whose chairs are in use for at least 30 hours per week. Other requirements are that chairs should have sling seats, should not be either reclining or semi-reclining, and users should already be using a wheelchair cushion or need one.

If you are interested and live in London or the Western Home Counties contact Mrs S. Tuttiet on 01 828 9811, ext 2494/2588

• The National Bureau for Handicapped Students has changed its name following decisions made at its annual meeting. The new name is to be 'Skill: National Bureau for Students with Disabilities' and will be launched later this year. The address continues to be: 336 Brixton Road, London SW9 7AA. Tel: 01 274 0565.

• Tripscope is a recently established information and advice service on travel and transport for disabled people. A registered charity, it was founded by Claudia Flanders, OBE, JP, widow of the late Michael Flanders, and she is now company secretary. Tripscope makes transport information freely available to those organisations helping disabled people or the elderly to plan journeys. The aim is to allow such organisations to obtain specialised advice and assistance by making a single phone call. Eventually it is hoped the service will be able to open up to allow individuals to make contact direct, but at present it is operating through organisations which help disabled or elderly people.

Brian Howard who formerly managed the £5 million Taxicard Scheme for disabled people has joined Tripscope as the Development Officer.

For more details ring 01 994 9294.

• The Booster Town and Country scooter has been awarded the Design Centre Selection - the black and white triangle familiar the world over as a symbol of good quality and design. It is the first and only electric vehicle for the disabled to receive this award.

Peter Baker, Managing Director of the Huddersfield family company that produced it - Booster Electric Vehicles - said "We are very proud of our achievement. As an independent company it is a real feather in our cap...".

• Castle Priory College, run by the Spastics Society, is holding a workshop on 'Working with the pre-school child with special needs', November 18-20 this year. It is designed for home liaison teachers, pre-school counsellors, health visitors and other people working with special children and their families. It is likely to be of most interest to those involved with severe developmental learning or behaviour difficulties caused by mental or physical disorders. It will not give detailed input on the management of severe sensory defects.

Fees and further details from Castle Priory College, Thames Street, Wallingford, Oxon, OX10 0HE. Tel: 0491 37551. Course No 24/124

Not the end of the world -

PART TWO

Continuing from the last issue - the diary of the first four years of CHRISTINA who has spina bifida and hydrocephalus, written by her mother

Christina, aged about 2

CHAPTER 7: Courage

It didn't take long for Christina to settle down at home again, and after just two days it seemed that we had never been away. Only the bald patch on her head remained to remind us.

The summer holidays were coming up and the boys would be home from school and looking forward to picnics and outings to the beach. The weeks sped by and Christina's bald patch had soon completely grown over.

Summer 1984 was memorable. The weather was sunny and hot so we were able to go to the beach a lot which the children simply loved. This time though there was the added bonus of Christina being able to join in.

Christina wasn't too bothered about her clothes coming off; she just got on with the job of playing in the sand. I even felt happy having her boots off, feeling that the sand was so soft and fine that I didn't have to worry about her damaging her feet. Christina had no feelings in them and so would be oblivious to any damage that might be happening. Left without boots on, her toes would often become bent backwards which on a hard floor could have caused permanent damage. On the beach though, she was much less vulnerable. As soon as she was changed into her beach outfit, the boys covering her feet with sand; this always brought squeals of delight from Christina.

If the weather wasn't suitable for the beach we would set out to the country so our Summer was full of fun.

I began to appreciate Christina's character. She was very brave. One of the nicest times was in the bath. David would ask her to hold her leg up to him and she would lift her left leg using the left hand to help the weak leg muscles. She learned very quickly to compensate for one weak limb. Her right leg, however, was a little stronger so she was able to lift that without even attempting to assist it. She could only lift it for a little while, but for her it was an effort which she bravely executed. She always tries her very best. Her courage is quite overwhelming. David and I have never thought why we were chosen, even at out lowest times. In fact we both felt privileged in a way to have been given such a beautiful, brave little girl.

Major decision

The Christmas holidays were drawing to an end with a New Year about to begin. The last one, 1984, had been very eventful with many major decisions made. One of these decisions was that David and I had finally agreed, after talking about it for nearly a year, that we would like to have another child. I made an appointment to see the doctor so that I could inform him and also to ask his advice as to how we could prevent spina bifida. I must say that I dreaded this first visit, fearing that the doctor would try to persuade me that with four children, one of whom is handicapped, that perhaps it would be wiser to be satisfied with the children I had, or advise me to save myself the work as well as the worry of bearing another handicapped child. Mercifully, he said neither of these things. He respected us, knowing that the decision to have another child had not been taken lightly and offered his help immediately. He gave me a prescription, telling me that Folic Acid and Pregnavite were recommended and that I was to take them for a period of two to three months prior to becoming pregnant.

CHAPTER 8: New life stirs

The beginning of 1985 brought with it the news of the beginning of our baby's new life.

Christina was making good progress with every passing day. Every Tuesday would be spent at the assessment unit in Truro for physiotherapy with Jan in the mornings and hydrotherapy in the afternoons. The staff at the unit were marvellous. There was always a friendly caring atmosphere. Christina loved going and always thought of it as going to school, thinking that she was just like her brothers. She had started to walk a lot better with the crutches by this time, finding that it gave her a great deal more independence than she had before. But it did mean that when we were in the garden we had to be extra specially careful watching as she would quickly disappear around the front of the house and we were afraid that she

continued on next page

- the start of a new one

All the family on Par beach. David Jnr is the one being buried!

would fall down the steps. She thought that it was great fun sneaking down the path and making us run after her. She would laugh so much at this that invariably she would fall over. The boys found that they had to treat her with a bit more respect or they risked one of Christina's crutches whizzing around their ears. We do not let her get away with being naughty. She has to live by exactly the same rules as we expect the boys to live by. She has a very strong will so this doesn't go down too well at times, but we persevere with her and eventually she understands that she is no different to the boys, even if she does grumble a little about it.

As time went by, I became happier and more contented to know that I had done my best to prevent the new baby from being born with spina bifida. I had not spent every spare moment thinking or worrying about it; every now and then a thought did enter my mind that the same might happen again but this was quickly replaced with an optimistic thought that I should hope and that all would be well.

We had various responses to having another baby. Some people thought that we were foolish, silly, stupid or plain irresponsible. Some asked if it was 'a mistake'. Well my thoughts were that we had planned our baby, with much thought and consideration as to what the consequences might be, and it must really not matter what others thought.

CHAPTER 9: Tears of joy

Once in hospital, I knew it could not be very long before our baby was born and all the months of wondering would then be over. I felt nervous. How I hoped that all would be well. But if it wasn't, I would cope, I told myself.

Although I was nervous I was also feeling very excited. Unexpectedly a very hard contraction came, leaving me no more time to wonder, and it was followed just a minute later by another hard contraction.

David woke up then, with me asking him to call the sister and to open the window for me as I was so hot. A nurse came quickly, opened a sterile pack, prepared the bed, and soon after baby was born.

I sat up to see if all was well. The sister picked our baby up and ran her finger along its back and said that she was fine and as far as she could see there was nothing wrong at all. She handed her to me. She was beautiful. I cuddled her, with David holding us in his arms. We could hardly believe that she was well. We were so happy. Our baby weighed in at 7lb 14ozs. We named her Katie.

Off to school

Time sped by and soon the New Year came. We were given some really wonderful news then - Christina would be able to go to the same school as the boys - Charlestown C P School. The school was having a special changing room with a toilet and a shower built. Christina was delighted that she would be able to go to school with the boys.

It was August by then and we celebrated Christina's fourth birthday How she has grown and progressed in four years. She walks well with her crutches and has become quite independent. She will be starting school in September, just in the afternoons at first, and then full time hopefully by the following Easter term.

Although I am happy for Christina to be able to go off to school, I am feeling a little sad. Its the end of the four years hard, but rewarding work - a major milestone for David and I. At the same time it will be the beginning of a very challenging time for Christina, but then she is well used to these.

I would not have changed any of the years we have been through and if I sometimes catch someone giving my family a sympathetic look, I think to myself that if only they knew how privileged we feel to have such a courageous member in our little family, who is, at the same time, just like the rest of us - a real blessing from heaven.

All in all, she is definitely the best thing that has ever happened for all of our family

School photo. From top left to right: David Jnr, Andrew, Katie, Christina and Peter

APPEALS NEWS

Be on your guard!

We have been informed of an unfortunate situation in which a local street and house-to-house collection was organised and at which a previously unknown individual presented himself at the gathering point, announced his desire to help, was issued with collecting boxes and has not been seen since.

A few months ago another individual was convicted of running bogus raffles, ostensibly on behalf of ASBAH.

Unhappily, it is necessary for us all to be on our guard against dishonest people of this kind who can damage the whole credibility of charity collectors in general and ASBAH collectors (local and national) in particular.

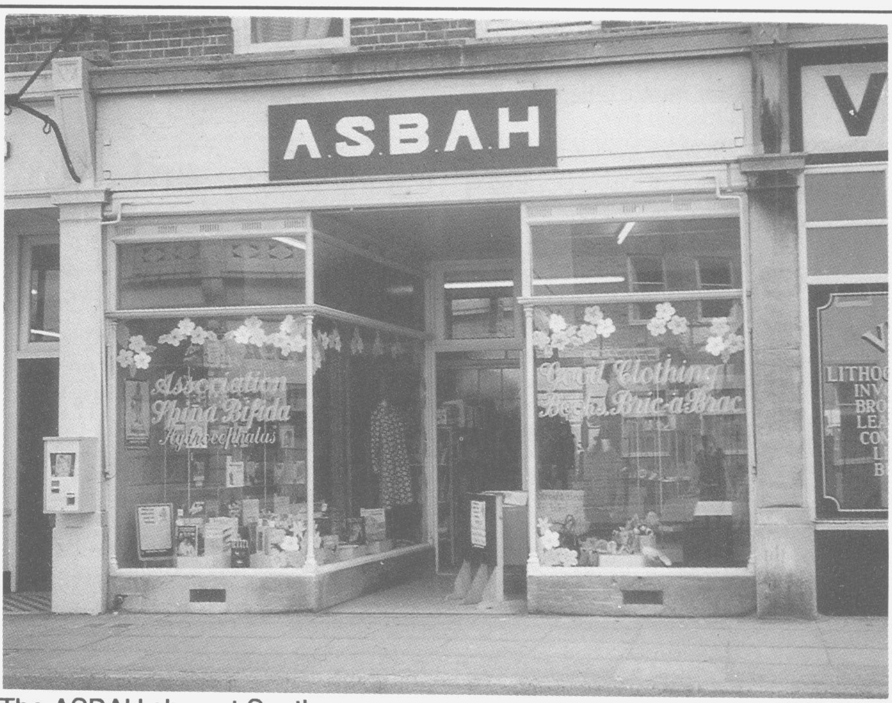
Shopping around for new business

We are continuing our efforts to extend our charity shops. Many properties come to our notice but for all sorts of reasons very few actually get established.

However, our shopping around is proving successful in Wales. In August, we opened a new shop in Pontardulais, near Swansea, and in September, we hope to follow with a shop at Gorseinon near Swansea. Both of these will be managed by Mrs Solange Davies, the wife of our West Wales fieldworker. We are looking at a property at Ebbw Vale, which, if it materialises will come under the control of Mrs Joyce Hodge - formerly one of our fieldworkers - who now looks after our shop at Risca near Newport. Negotiations are also progressing for a property at Porchester in Hampshire.

Our shop at Swaythling, Southampton, is on the market due to disappointment with the level of trade achieved. A shop at Maidstone, which was to have been a joint enterprise with the Kent Association, has had to be abandoned because the management for which we had hoped is no longer available.

Fareham, our best shop in turnover terms, had a near escape from serious damage when a motor workshop on the floor above caught fire. The local newspaper referred to 'a fireball', a frightening description indeed.



The ASBAH shop at Southsea

Regionalising the conversation

Plans are afoot to give the familiar 'Chatathon' - now known as the Conversationalist of the Year - a further update by the possible introduction of regional qualifying heats, run by local radio stations.

Local associations whose areas might be involved will be fully informed and consulted.

Please do let LINK know of any fund-raising efforts of special interest in your area. New ideas are also welcomed, and may inspire others to have a go.

Action man

John Saxelby, who has hydrocephalus, a few months ago raised money for ASBAH by cycling from Paddington station in London to his home in Banbury. John now intends to raise more money by a sponsored darts marathon on Sunday October 30.

This event will take place (indoors, of course) at the ground of Reading Football Club. At a time when the prestige of English professional football is low, it is pleasing to be able to report that we have received tremendous help from the Reading club at no cost to ASBAH.

Oldham offers

We have also received a generous offer of help from Oldham Athletic and we are considering how best we can take advantage of their kindness.

Following the hounds

As reported in July/August issue we are holding, in collaboration with the Hull local association, a charity greyhound meeting in Hull on October 8. Contact Appeals department at national ASBAH for more details.

Our third charity greyhound meeting at Wimbledon will take place on Tuesday February 21, 1989 - a note for the diaries of those who feel like going to the dogs!

Advertising

FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

Rates: £3 for 30 words max; £4.25 for 30-45 words; £5.50 for 45-60 words.

Cheque or postal order payable to 'ASBAH'

Adverts for the next LINK (Nov/Dec) should be in by October 22. Send to: **The Editor, Mrs Sue Gearing, The Gables, Long Lane, Wrington, Avon, BS18 7NE. Tel: 0934 862279**

HOLIDAY ACCOMMODATION

BORTH, Nr Aberystwyth. 6-berth de luxe holiday home. Licensed site. Suitable for wheelchair users who live independently. Details: Mrs J. Carter, 1 Meadow Road, Craven Arms, Shropshire.

ISLE OF WIGHT. Very well equipped chalet with easy wheelchair access at **Brambles Chine, Freshwater.** Sleeps 6. Indoor heated pool, club, shop.Details: Ring or write: Mrs S. Gully, Old Princelett, Apse Heath, Sandown, Isle of Wight. Tel: 0983 863354

SELSEY, Sussex. Six berth purpose built fully equipped mobile home. Ramp access. Site near sea. Pool, club, etc. Details: Mrs C. Bugden, 27 The Grove, Sholing, Southampton SO2 9LT. Tel: 0703 444921.

EXCHANGE AND MART

NIPPI 50CC, RED Fully automatic. Perfect running order. Taxed for 12 months. £1,200 o.n.o. Callers welcome. Tel: Bangor 352366.

1983 DODGE 1100 High top car, derived van. Special 'hubmatik' conversion for wheelchair passenger (stays in chair). Ziebart rustproofed. MOT - Feb 1989. Mileage 14,500. For sale: £2,500. Tel: 0403 67150 (Horsham)

MINI METRO 1986 D Reg. Low mileage (2,500 miles). Hand controls, covered wheelchair hoist. Very good condition. Cost £6,800 new. Reasonable offers please around £4,500. Contact: Tina Van Hove Tel: 01 968 8317

COMPLETE HOSPITAL BED. Foot pump action for adjusting height. £350. also **ELAP ROTATING CAR SEAT** for disabled or elderly passenger. Fits most cars. £65. Both items as new. Tel: Mrs Wilson 061 223 7336 (Manchester)

CARTERS CRUISER ELECTRIC WHEELCHAIR. Kerb climbers, battery charger, blue chrome frame. One hours use only. Immaculate. Cost £1,420. Offers in the region of £1,000. Reason for sale: purchased Batricar. Tel: Cindy Bowring. 0329 662513 (Fareham, Hants)

SPORTS WHEELCHAIR Red/black. Very good condition, including spoke guards and pump. £200. Tel: 0273 413060 (Portslade, Sussex)

BEC HORIZON 40 ELECTRIC CHAIR. Kerb climbing. Dual action (can be controlled by attendant ifnecesssary). Perfect condition. Cost new: over £1,700. Will accept £800. Tel: Mr Clough 0253 22268 (Blackpool)

EXCHANGE AND MART (continued)

PORTABLE ELECTRIC WHEELCHAIR Purchased December 10, 1987 for £1,535 Used only twice. Bargain at £900. Contact V. G. Morris Tel: 0842 2047 (Norfolk)

PLOUGHMAN'S REST is a holiday cottage all on one level about one mile from the lovely old village of Shipton-u-Wychwood , and three miles from the Cotswold town of Burford. Available all the year round. It is described as a luxury unit with wide doors suitable for wheelchairs. All facilities including microwave and colour TV. Kitchen, lounge/dining room, bedroom with double and single bed, ensuite bathroom with shower, bath wc with handrails. Contact Mr Hartley (0993) 830261

IMPORTANT NOTICE FOR ALL LOCAL ASSOCIATIONS

If you want your association's holiday chalet or caravan etc. advertised in LINK please be sure to send in details, and cheque with order, for 1989.
Indicate in which issues of LINK next year you would like the advert to appear.

Send to Mrs Sue Gearing the Editor, either at National Officer or to her home in Wrington (address above).

WHAT SHALL I WEAR TODAY?

A STUDY DAY
highlighting the dressing and clothing problems of adults who acquire a physical disability

DATE: November 1, 1988

TIME: 9 am - 4 pm

VENUE: William Merritt Disabled Living Centre,
St Mary's Hospital,
Greenhill Road,
Armley, Leeds LS12 3QE

COST: Disabled people/carers - £10
Professionals - £15

For further details and an application form please contact Clare Scott at the William Merritt Centre, or telephone Leeds (0532)793140.

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