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Association for Spina Bifida and Hydrocephalus/ASBAH 10p May/June 79

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Association for Spina Bifida and Hydrocephalus

# Towards Independence

## A training programme for young handicapped adolescents run by LIFT—Young ASBAH.

THIS ASSOCIATION is particularly concerned with the problems of the large number of adolescents and young adults with spina bifida and hydrocephalus. Improvements in the surgical treatment of babies with these conditions, in the early 1960's, have resulted in a dramatically increased number of teenagers and young adults, disabled by spina bifida and hydrocephalus, now alive. These people, and their families, face numerous problems, including social barriers of incontinence and inadequate preparation for further education, training, employment and leisure. In an effort to help young people overcome some of these problems, National young ASBAH—LIFT, along with several Local Associations and childrens hospitals, has taken positive action in the form of Independence Training Weeks.

Photo: Len Hooper

Michelle and Graham tackle the everyday problem of what to buy for the meals ahead. They learn how to keep to a budget and at the same time provide a balanced diet.

# Training must begin at home, but . . .

INDEPENDENCE is an attitude of mind as a series of skills and obviously any training in independence should begin in the home and from a very early age. But parents are not always sure of the best way of teaching their own children, and are often not given enough help and advice. Domestic routines may not allow for a mother to encourage her child to dress himself if this takes a long time, and the wish to help a disabled child is understandably very strong.

There is a need, therefore, for training courses away from home, but to be effective these must be combined with detailed follow-up with families and schools so that newly acquired skills can be consolidated and so that the youngster's changing perception of his own abilities is matched by a recognition of his increasing independence in those with whom he lives.


Photo: Jan Tomlinson

**Joanne, 7 ½ yrs, learns to master putting on her own calipers, as well as dressing and washing herself. It's all part of her own personal care routine.**

# Just what goes into a week of independence training

INDEPENDENCE WEEKS are designed to encourage personal and social independence in all aspects of life, including the management of urinary appliances and daily living skills. Throughout the week the emphasis is on encouraging young people to make their own decisions, and to learn from their mistakes.

Over the last year, National ASBAH has run four Independence Training Courses; three designed for the 16+ age group, and held at our residential home in Ilkley—"Five Oaks", and one for young people, aged 9-13 years, at New Mossford, the Dr Barnardo's home in Essex. Fees are charged according to the centre used, but will be in the range of £75-£95 per week in 1979.

Each course lasts a week, and although the programme detail depends on the age of the youngsters attending, the morning and evening sessions are devoted to helping them develop their own personal care routine, such as the management of their own urinary (and other) appliances, washing, dressing, transferring from wheelchair to bath, bed, car, etc. Every course includes a session on diet and the importance of properly balanced meals; menu planning and budgeting, shopping and finally the actual preparation and cooking of meals. Additionally, by cooking their own meals, the students learn to cope with restrictions of a kitchen not specifically designed for wheelchair users.

The courses are staffed by National officers and volunteers, who work with students on a one-to-one basis as far as possible, with the backing provided by other professionals such as therapists and appliance nurses from Downs Surgical Ltd. Before anyone is accepted on a course, a home visit is arranged by either a National Officer, or one of ASBAH's Field Officers or Social Workers, to discuss the programme for the week with the young person and parents in order to decide whether the particular course will be suited to the individual needs.

Follow-up visits are equally essential if the week is to be really helpful to an individual, and we have tried to liaise with schools, careers officers, social workers, etc, wherever possible. However, although this is possible in some cases, ASBAH is concerned that no facilities exist for systematic follow-up procedures to be established through many local authorities.

# A typical independence week for the 15+ age group

| | SAT | SUN | MON | TUES | WED | THURS | FRI | SAT |
|---|---|---|---|---|---|---|---|---|
| BREAKFAST | FIVE OAKS BREAKFAST | | | GP 3 | GP 1 | GP 2 | FIVE OAKS BREAKFAST | |
| | | | | COOKING OWN BREAKFAST | | | | |
| MORNING | Arrival of staff and last minute arrangements | PERSONAL PROGRAMME | | | | | | |
| | | Self-care<br>Downs Nurses | Diet and Menu Planning | GP 1 Washing and Ironing<br>GP 2/3 Baking | GP 3 Washing and Ironing<br>GP 1/3 Baking | Visit to Remploy (Leeds) | 10–2.30 Shopping | 9.30–10.30 Discussion on Course<br>Preparation of Buffet |
| LUNCH | FIVE OAKS | | Lunch at Ilkley College | FIVE OAKS LUNCH | | | Lunch in Town | Buffet |
| AFTERNOON | 3.00 pm onwards Young people arrive | 2.30–4.00 Community volunteers Discussion | 2.00–4.30 Shopping in Ilkley | 3.00 pm What is Spina Bifida and Hydrocephalus? | CRAFTS<br>GP 2 Washing and Ironing | New Mossford Film and Discussion on Education, Training and Employment | Discussion Personal Relationships | 1.00 Buffet Discussion with Parents<br>Depart |
| HIGH TEA | FIVE OAKS HIGH TEA | | GP 1 | GP 2 | GP 3 | — | Five Oaks | |
| | | | COOKING OWN EVENING MEAL | | | | | |
| EVENING | Introduction and Discussion | CRAFTS | Free Evening | Folk Evening in Ilkley | Safety and Discussions | Visit to Restaurant | 6.30–8.30 Personal Hygiene—Discussion | |
| | PERSONAL PROGRAMME | | | | | | | |

## Courses for 1979

NATIONAL Young ASBAH is planning four Independence Training Courses in 1979, and has expanded its programme to include all age groups from nine years and over. Additionally, we are involved in courses run in conjunction with, or by, Local Associations and children's hospitals. Obviously, these courses will only cover the needs of a small minority of young people—many will not be able to take part in a course due to our limited resources. The Association hopes that Independence Training will soon become fully integrated into the curriculum in all schools, with teachers, therapists and care staff working together on the training programme. Parents should also realise the importance of working towards independence at home, so that from an early age young people can take full advantage of the opportunities available to them. However, Young ASBAH will continue to run courses and give assistance to local projects in the field of Independence Training as long as it is necessary.

**Stephen, mixing up another cordon bleu masterpiece! Both men and women should be able to cope with basic cookery.**

Photo: Len Hooper


Photo: Len Hopper

Michelle and Graham, having enjoyed one of Stephen's concoctions, no doubt, learn that there is another side to mealtimes apart from eating—the washing up!


Photo: Len Hopper

Stephen does another important household task—ironing. This is an everyday skill which is not traditionally the male's role. But if he wants to cope on his own he's got to learn it all.

## The views of two young people who attended Courses

### ANGELA PAGE, 22, from Bramley, South Yorkshire

AFTER reading about the Independence Course which was to be run at Five Oaks in Ilkley, I did think I would like to go, however, I am not used to mixing with a lot of other people, disabled or able-bodied, and I was rather worried about this. After speaking to Jan Tomlinson on the telephone, at which time she told me a little about the course and made arrangements to call and see my parents and myself, I felt much happier about going on the course. So when November 11 finally came, I was looking forward to going very much.

There were six disabled people on the course, which ran for a week. Each disabled person had an able-bodied helper, who would help if asked. The helpers were not much older than ourselves, so we got on well together, and had a lot of fun during the week.

My main problem was not being able to get in or out of the bath without help, so when I wanted a bath while I was at Five Oaks, Jill Vernon, ASBAH's Aids and Appliances Officer, showed me some of the many different aids available from your local Social Services Department.

The six of us were split up into two's when we did things like menu planning; and we then went to the local shops to buy our own food for two meals which we cooked ourselves. The meals we cooked were breakfast and tea. This was great fun as a lot of us cannot do this in our own homes because things are too high or too low for us to reach. We also had a day to try our hand at doing some washing and ironing.

We were also shown different crafts, such as leather work or how to make a perfumed candle. The craft sessions showed us what we could do during our leisure time, and also a way we could possibly earn some money.

One day we were taken to look round a local Remploy, which is a firm run on the same basis as any other, with one main difference—the employees are all disabled in some way. This was followed by a discussion on employment and further education for disabled young people.

On the Thursday evening, we were taken to a restaurant and left to order our own meal while the helpers went somewhere else to eat. This experience gave us a chance to cope on our own without parents or other adults around.

Apart from the things I have already told you about, we had a talk on "What is Spina Bifida?" and the different ways it affects us. I felt that this was a very good topic as a lot of parents find it difficult to talk to their children about this.

On Friday evening we were given a talk by a hairdresser about the different problems you can have with your hair, and how to make the best of yourself. Saturday morning we helped with the final arrangements of the buffet, which was to take place when our parents arrived.

When I was about to go home again, I couldn't understand why I had my doubts about going to Five Oaks, and would recommend that you go on a course if you have the chance.

### GILLIAN CLAYTON, 10, from Colchester, Essex

THANK you very much for having me at the Independence Week at New Mossford. I learnt quite a few things, like changing my bag, carrying a tray, going out shopping and washing my hair myself, (well, I didn't really wash my hair myself, I put the shampoo on). I need more practice carrying a tray because I get a bit nervous, but I will get used to it one-day. However, I am managing quite well with my bag by myself and my mum is very pleased indeed, as are the nurses at the hospital—I quite enjoy doing it myself as well. Besides learning to be independent, we also went on visits and social evenings. One day we went to a museum.

For more details of the courses being run in the coming year, or more information on Independence Training, please contact:
Jan Tomlinson, Young ASBAH Officer, Tavistock House North,
Tavistock Square, LONDON, WC1H 9HJ. Tel: 01-388 1382

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Association for Spina Bifida and Hydrocephalus/ASBAH

Correspondence to ASBAH at the National Office:
Tavistock House North,
Tavistock Square,
London WC1H 9HJ.
Registered Charity No. 249338
Tel: 01-388 1382/5

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**PLUS 4 page pull-out supplement about LIFT Independence Training Weeks.**

**THE NEWSPAPERS and television generally report the sensational and controversial aspects of trade union activity such as strikes and other industrial action. Most of the steady day to day work of trade unions and the TUC goes unreported, including our efforts to improve the employment position of the disabled. I am grateful for the opportunity to outline some of our work in this respect.**

We recognise that many disabled people face even more serious problems in obtaining suitable employment than other unemployed people. The present rate of unemployment of disabled people is well over double the rate of general unemployment, which is itself unacceptably high. There are various reasons for this, ranging from misunderstanding and lack of knowledge of the capabilities of people with disabilities on one hand to problems of access, and adaptations of machinery and equipment on the other.

Equally, however, it is important to remember that the disabled unemployment rate very much follows the trend of the general rate of unemployment and that the job prospects of disabled people would benefit substantially from a general improvement in the nation's economy. The TUC has pressed for economic policies that will produce real and sustained growth in the nation's wealth of at least three per cent each year.

As regards the special employment needs of the disabled, the TUC has three representatives on the Manpower Services Commission (MSC) which is generally responsible for the State employment and training services. In February 1978 the MSC published a programme for the future improvement of its specialist services for disabled people. This programme, "Developing Employment and Training Services for Disabled People", was drawn up after consultation with the TUC, and proposes a real increase of 13 per cent over the next five years in MSC expenditure on its services for disabled people. This means further improvements in the disablement resettlement service, higher standards of training and improved access to training arrangements for the disabled, expansion of employment rehabilitation facilities, and creation of up to 200 more sheltered employment places each year.

The TUC has actively supported the new "Positive Policies" approach adopted by Disablement Resettlement Officers with more time spent by DROs talking to industry and persuading companies to provide greater opportunities for disabled workers. The new job introduction scheme and capital grants and improvements in the help with fares to work will assist DROs to fulfil this task more effectively. The TUC had been pressing for a capital grants scheme for several years until it was eventually introduced.

To be successful the "Positive Policies" strategy requires appreciation at the workplace level of the special difficulties that may confront some disabled workers, but equally of the jobs that disabled workers can do if given a fair chance. Len Murray wrote last year to all unions urging them to make "Positive Policies" known to all their members. The TUC has also proposed changes in the structure of local Disablement Advisory Committees, which already have local trade unionists on them, so that they reflect more strongly the interests of both sides of local industry, who can then be more active and effective in assisting DROs in their work.

Although our primary aim is to assist disabled people to find suitable employment in open industry, trade unions appreciate that for some severely disabled people sheltered employment may be the only option. Although sheltered workshops are expensive, we are adamant that society has a clear duty to meet the needs of those who work in them. Through the representatives on the MSC, the National Advisory Council for the Employment of Disabled People and the board of Remploy Ltd, the trade union Movement has sought to promote and expand sheltered employment; and a number of measures are now being taken to improve the operation and management of sheltered workshops.

**TREVOR MAWER, TUC and a member of ASBAH's Education, Training and Employment Committee.**

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LINK: The last date for material for July/August LINK is June 1. *Write to Mrs Susan Gearing, Editor, LINK, at ASBAH.*

The yearly subscription for LINK (UK) is £1.15, which includes postage. While every care is taken to ensure the accuracy of information published in LINK the publishers can accept no liability.

# With holidays in mind . . .

SPECIAL interest holidays—in subjects such as philately, chess, bridge, etc—are to be organised by Hertfordshire Association for the Disabled if there is enough demand. It hopes to organise special interest weeks for the Autumn in its purpose-built hotel (22 beds) at Clacton-on-Sea, Essex. If you are interested, write to Holiday Organiser, Herts. Association for the Disabled, 2 Townsend Avenue, St Albans, Herts.

■ ■ ■

IRISH Holidays for disabled people are being arranged for the first time, on a working farm in the hills above Lake Killarney. The first holiday will begin on September 3. For details contact: Mrs Ashton Edwards, 'Arbour', 11 Broomfield Road, Kew Gardens, Richmond, Surrey. Tel: 01-940 2276.

■ ■ ■

*THAMES Cruises from Radcot—journeys of between two and eight hours—can be organised for parties of up to 48 people, including about eight or 10 wheelchairs, on board the traditional narrow boat, The Battersea. The boat is open-plan with removable seats and a passenger lift is installed for easy access. For booking form and more details contact Thames Cruises, c/o Nicholas Elwes, Wanborough Manor, Guildford GU3 2JR. Tel: 0483 810484.*

■ ■ ■

*BRITAIN for the Disabled.* **This useful free booklet is available from the British Tourist Authority, 239 Old Marylebone Road, London NW1 5QT. It aims to help disabled people arrange their holiday with little fuss and to enjoy it to the full.**

**There is information on medical arrangements, transport and accommodation.**

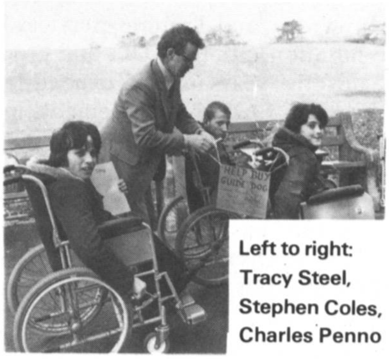
# Zachary fund still open

THE PROFESSOR Zachary Fund, launched at the end of 1977, to finance special projects for young people with spina bifida or hydrocephalus, is still open.

Some people may want to travel abroad to further a particular interest or career, others may want to purchase musical instruments, text books, or sports equipment, or need special furniture—perhaps to enable them to manage at university or college.

These are only examples or some of the ways in which the fund has been used so far. Involvement of teenagers and young adults is the most important factor, and this means that projects supported by the Fund could be quite large or very small.

Young people interested in applying to the Fund, or finding out more about it, should write to National ASBAH office.



**Left to right: Tracy Steel, Stephen Coles, Charles Penno**

# 15 Children raise £350

FIFTEEN physically handicapped children from Dame Hannah Rogers School, Ivybridge, South Devon, spent three hours negotiating a tough half-mile circuit of footpaths in Plymouth's Central Park to raise over £350 for the Guide Dogs for the Blind Association. The children—some in wheelchairs—completed 118 laps totalling 59 miles.

The sponsored trek was the idea of Tracy Steel, 16, who has spina bifida, and two spina bifida boys, Charles Penno, 12, and Stephen Coles, 15, clocked up 14 laps. Tina Pitts, 15, who also has spina bifida, completed eight laps. Between them these four covered 23½ miles of wheelchair travel and raised £120 of the £350 total.

# Passengers —New Law on payment

THE LAW on car sharing for payment has recently changed under the provisions of the 1978 Transport Act. Seven passengers can now be carried at separate fares, provided you are not in the business of carrying passengers.

The main condition is that journeys must be made without previous advertisement to the public and that passengers are to be carried at separate fares. However, voluntary organisations can advertise, in their publications, car-sharing involving separate fares in relation to particular activities or outings. More details from the Department of Transport, quoting Circular 9/78.

# 1981—Secretary takes up job

INTERNATIONAL Year for Disabled Persons will be 1981 and ASBAH will be taking an active part in planning events. The newly appointed Secretary to the Voluntary Bodies Committee for the International Year is Stephen Crampton, a member of the National Council for Social Service, and he will be taking up his duties this month (May). LINK will keep you in touch with plans.

# Front Cover Story

**CONGRATULATIONS to Alan Robinson and Shirley Oliver who are pictured after their marriage at Prestow near Brighton.**

**The couple have made their home near Sheffield where Alan is company secretary of a ceramic tile business and Shirley is an occupational therapist.**

**In his spare time, Alan who has spina bifida—is a keen basketball player and will be competing in the National Games at Stoke Mandeville this June.**

Photo: EBA Studios, Newhaven.

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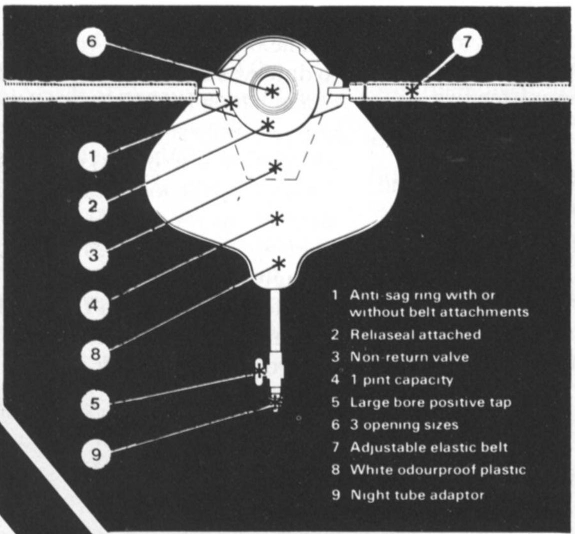
Home visits can be arranged if it is impossible for an ostomist to visit one of our many stoma centres throughout the country.
Please write or telephone Salts if you have problems and help will be forthcoming.
The appliances shown below can be tried by you, free from charge and without obligation.

## LW URINARY POUCHES

are complete appliances and can be worn without any additional accessories, though some ostomists prefer the added feeling of security which LW accessories can provide.
LW is disposable, is odourproof, is soft and rustle free, is self-adhesive, and can be worn for up to one week before changing.
Cotton bag covers can be provided, and alternative adhesives are available for use with pouches without Reliaseal attached.
3 opening sizes available: 1″, $1\frac{1}{4}$″ and $1\frac{1}{2}$″.

## LIGHT WHITE ILEOSTOMY POUCHES

can be worn without any additional accessories, though some ostomists prefer the added feeling of security which LW accessories can provide.
LW is disposable, has bag covers, belts, closures, stabilising rings, is supplied in two capacity sizes, large and medium, odourproof, can be worn for a week without anyone knowing, and it looks as good as an appliance can look.
Any ostomy adhesive and sealing washers are suitable. None can harm the tough, soft plastic. Reliaseal is highly recommended.
3 opening sizes available: 1″, $1\frac{1}{4}$″ and $1\frac{1}{2}$″.



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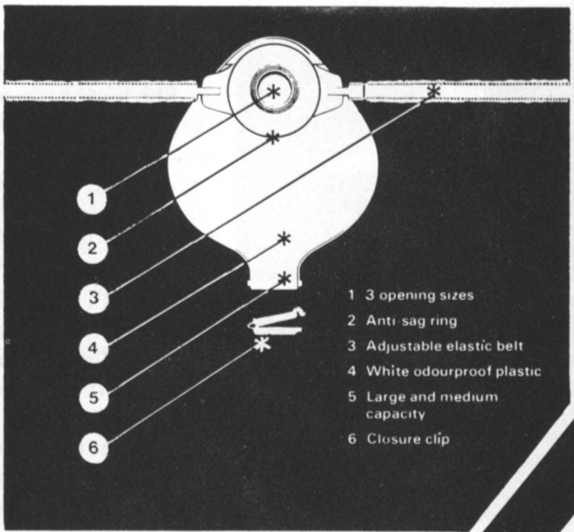

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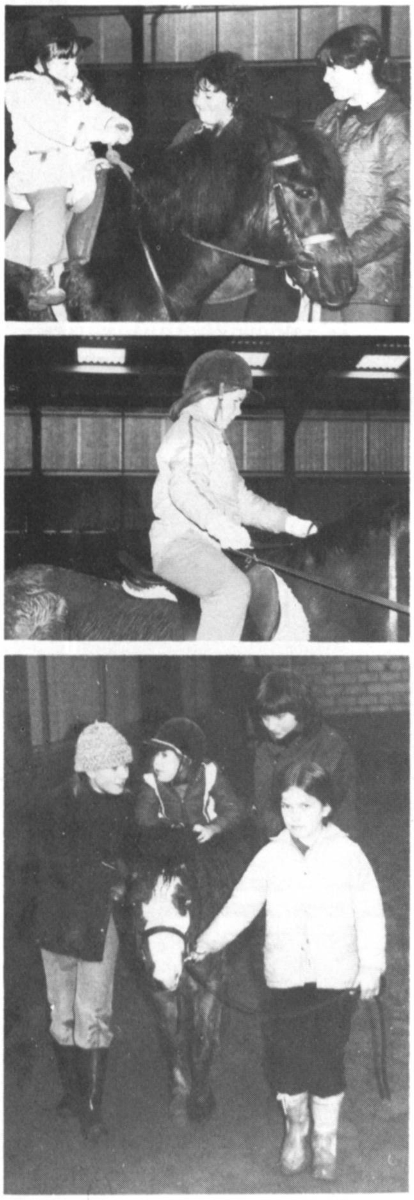
# Bournemouth —and the problems of keeping up with changing needs



Above — Saturday mornings at the Fortune Jubilee Riding Centre at Avon Tyrell for young members of Bournemouth, Christchurch and Poole association.

**BOURNEMOUTH, Christchurch, Poole and District Association has two big things going for it—the area it spans is a mere 15 miles across, and so communication between all members is easy, and this sunny, holiday area seems to generate a feeling of benevolence, so money-raising isn't difficult.**

Like other local associations it is kept oiled by the hard work of committee members—people like Mrs Rosemary Creech, Vice-Chairman, and Richard Frake, Secretary—whom LINK went to visit in March.

Although Rosemary is not a qualified social worker, she deals with the welfare work of this local association in a voluntary capacity (as well as holding down a job and looking after her husband and three children!). Problems range from helping to get the social services to instal a chair lift in the home of a severely disabled teenager, to giving moral support and practical help to the mother of a spina bifida child when her marriage was threatened.

It's a job she has picked up as she goes along, based to some extent on her own experiences in bringing up her children, including nine-year-old Teresa who has spina bifida.

She joined the committee five years ago, shouldered the responsibility of writing the newsletter, and then gradually found herself involved with welfare work as it became apparent that there was a need.

"I find I can often get through to people where others can't, simply because I am a woman, and because people either know me or know my name" said Rosemary. She adds it's important to try to have a good working relationship with the social services in the area.

The association which separated from Wessex ten years ago has more than 70 members—36 children, 3 adults with spina bifida, and 35 associates.

Social gatherings are organised fairly regularly, not so much for the children, as for the parents—to give them a much needed break and a chance to relax together. The children have their treats too, a Christmas party and summer outing, and riding every Saturday has just been started at the Fortune Jubilee centre at Avon Tyrell. Plans are afoot for regular swimming sessions, too.

About 14 of the young members are in their teens, and reflecting this, the parents' last Christmas dance included those young people who had outgrown the normal children's party. But it is still a young association with ten children under five (the youngest is three), 12 of them up to age 11 and 14 up to age 16.

Richard Frake expressed his concern that the association had no idea of the number of spina bifida people—children and adults—in the area. There is no efficient way of contacting them or getting in touch with new parents, other than asking the hospital to give them the association's card.

## Confused

'But often new parents are too confused and upset to contact us for many months or years, and they may well have been glad of our support earlier' said Richard. ASBAH noticeboard cards are now being distributed to doctors' surgeries and hospitals to advertise the association more widely.

The biggest money-raising venture to date was £4,000 for the holiday chalet which is at Looe in Cornwall and proving very popular. The association also has its own minibus, donated by the local Ladies' Circle, although as the members grow up there are signs that it is no longer big enough.

"Money-raising isn't difficult' said Richard, "holidaymakers are very generous. One of their most

The oldest spina bifida member of the association, 67-year-old Violet Munden, proudly shows off her new electric wheelchair which was bought for her as a result of a sponsored walk by the tele-ads department of the Bournemouth Echo newspaper.

successful events is a mile of pennies which can bring in anything from £200-£600. The association is also a notable entrant—and prizewinner—in local carnivals.

The association may have a lot going for it, but it has problems, too. There are no residential special schools close at hand for those over the age of 11 and most of the young members have to go away out of the area to school—the nearest is 60 miles away. This has the effect of isolating them from their home, the association and neighbourhood friends. When they do come home for holidays and at the age of 16 they are like strangers and tend to retreat into themselves.

The future of their young members is very much in the minds of the association. It is reckoned that about a third of the teenagers should be able to hold down jobs in open employment. The rest will need some kind of sheltered work.

Rosemary has managed to build up a good relationship with the local careers' office, but the future of the young people is still very much in the balance when it comes to finding them a suitable occupation. One possibility is that the association will have to extend its work to meet the changing needs of its youngsters. It is considering running its own day centre to provide social activities, and somewhere to meet. The centre could also be run as some kind of sheltered workshop, taking in work from local industry. But the idea hasn't been discussed fully yet and obviously an ambitious venture of this kind needs a lot of planning and consideration.

## It's up, up and away for Keith

KEITH Milner, 11, is pictured above at the controls of the aircraft which he "co-piloted" for a flight over the Solway and the Lake District, with the pilot Mr Frank Broughton. Keith, who has spina bifida, and comes from Carlisle, is very keen on aircraft and flying, and making aeroplane kits. He longed to 'try out his wings'. Frank heard of this ambition and gave him the chance of flying with him . . . a flight that Keith will long remember.

Photo: Cumberland Evening News.

## Buffaloes buy Kent a hobcart

KENT Association has been presented with a hobcart, by the Gravesend and District Lodge of the Royal Antediluvian Order of Buffaloes to mark the International Year of the Child. The hobcart was presented at Gravesend Civic Centre to 10-year-old Christopher Paul of The Association.

## Hoe Down raises £1,400

LEEDS and Bradford Association received a cheque for more than £1,400, as the result of a 'Hoe Down' held at the farm of Mr J. Ambler at Denholme, near Bradford. The money will go towards a holiday chalet at Mablethorpe for Leeds and Bradford families.

ROY Castle, (left) popular comedian and currently presenter of the popular television keep fit programme 'Feeling Great' recently visited Sheffield Children's Hospital and helped the children there to feel much better—including 10-year-old Neil Dallison of Thurcroft, near Rotherham. Neil, who has spina bifida, is pictured with Roy Castle.

Photo: The Star, Sheffield.

Downs Surgical Limited
Downs Surgical Limited

# Double diversion—a minority problem

*Article by D. M. Forrest, FRCS, who is Consultant Surgeon at Queen Mary's, Carshalton. He is also a member of ASBAH National Executive Committee, and the Medical Committee, and Chairman of the Appliances Committee.*

**THE VAST majority of spina bifida patients suffer some difficulty in controlling the bowel and bladder. In a smaller number there is also risk of ill-health because of stagnation and infection, particularly in the urinary tract but also in the large bowel. Consequently, operations have been devised to divert the urine or motions so they discharge on the surface of the body where hygienic collection is possible.**

In some centres, urinary diversion by means of an ileal loop has been favoured for nearly all girls and a fair proportion of boys, while elsewhere, serious attempts are made by training, or other forms of collection, to preserve the natural route whenever possible.

Fortunately, control of the bowel is usually easier to achieve so that bowel diversion does not often need to be considered. Most patients have a sluggish bowel which tends to constipation and therefore the motions are solid and soiling is not a great problem. Nearly all patients achieve at least partial management of their bowels with one or more of the following measures: (1—a good all-round diet avoiding foods liable to cause diarrhoea, discovered by trial and error. Habitually loose bowels are of course disastrous if the patient has no feeling or cannot stop them acting. (2—medicines to slow down bowel activity and make the motions firmer. Less of a problem are bowels which act seldom. There is some danger of the whole bowel becoming grossly distended and ceasing to act altogether but parents often overrate the threat and try unnecessarily to get the bowel regular. (3—aperients (opening medicine) suit some patients but the most suitable one has to be found by trial and error. Often they cause looseness and colicky pain. (4—a suppository or enema every two to four days. This tends to have a more predictable action but if it fails to work the unpleasant alternative of (5—manual removal by a parent or nurse may be the only effective method and this may be unacceptable as the child grows older. Thus in a few cases where the motions are persistently runny or stubborn constipation makes an independent life impossible the alternative of bowl diversion has to be considered.

Naturally, a patient who has a urinary bag does not want to wear a nappy or disposable pad, so an operation to enable the motions to be collected in a bag may be welcomed. Only a few individuals have such a deformed trunk that there is no convenient site for the stoma or "cherry". Usually it can be placed symmetrically opposite the urinary stoma so the same belt can support both bags. The operation used is a *colostomy* that is, an artificial opening for the *colon* or large bowel, usually near its lower end. Whereas a urinary diversion once fashioned is almost impossible to put back, a colostomy can be easily reversed, so if the patient finds it impossible to live with, no great harm has been done. The bowel can be rejoined with a return to the previous state. As the contents of the bowel are more unpleasant and unmanageable than urine some patients find it impossible to become accustomed to a colostomy. Leakage can be more socially embarrassing and if the motions are very loose there may be irritation of the skin. Some patients have a lot of trouble with wind which cannot be controlled. By dietary control a regular pattern of bowel action usually develops so that the bag fills only once or twice a day and can then be changed. Some prefer to wash out the colostomy (in the same way as having an enema) in the morning so that the bowel will not work again and a cap be worn to replace the bag.

Even more than with a single diversion, it is important for fitting and adjustment of bags to be supervised regularly by a skilled fitter, able to try several different types of appliance in order to discover the best combination for the individual patient. It is very difficult to achieve satisfactory results when a personal fitting service is not available.

After urinary diversion there is sometimes persistent discharge of foul fluid from the disused bladder. This can be managed by occasional antiseptic washouts, or occasionally when persistent, removal of the bladder. Similarly, in the bowel, motion sometimes spills over and is discharged from the back passage. This should not happen if the two ends of the bowel have been carefully separated with the formation of an "end colostomy".

A trouble-free life with a double diversion demands careful planning, good surgery and personal appliance fitting.

# YOUR RIGHTS

## Part 2

**IT CAN BE a difficult and off-putting experience trying to claim a legitimate right or benefit. The complex rules and forms which the people who administer various schemes find so necessary can seem like enormous barriers to the claimant.**

**And it you add to these difficulties the all-too-common feeling that rights and benefits are in some sense charity, it's not surprising that a lot of people do not bother to claim at all.**

**Take Supplementary Benefits for example. Many elderly and disabled people are receiving Supplementary Benefit, often as a small amount on top of retirement pension, sickness or invalidity benefit. But more than 100,000 disabled who could claim it, do not.**

**Rights and benefits are not charity. They are not free handouts. They are simply basic supports which a civilised society extends to people at a time of exceptional need.**

**In this second guide to Your Rights LINK again draws on the "Disability Rights Handbook for 1979" which has been published by the Disability Alliance.**

**The full text is strongly recommended and is available from the Disability Alliance, 5 Netherhall Gardens, London NW3. It costs 70p (by post 85p) and there is a half-rate offer for orders of 20 or more from voluntary organisations concerned with disabled people.**

PART 1 of this guide to Your Rights appeared in LINK No. 61. As then we will begin with some important names and some advice on how to reach them.

General information is available from your local social security office—you will find it in the telephone book under Health and Social Security, Department of: and from advice centres. Leaflets will also be available from the post office.

Your local social services department provides personal and welfare services. It can be found in the telephone book under the name of your local authority . . . for example Essex County Council: and then under the heading Social Services Department you will find a telephone number for your area office.

It's important to remember that this guide is only an indication of rights and benefits that are available. Only by having your individual circumstances assessed will you discover if you qualify. You should ask.

In your area you may have a Welfare Rights Officer who will be found through the Citizens Advice Bureau, the Council of Voluntary Service, or the local authority social service departments. It will be possible for you to have an interview with an officer of the Department of Health and Social Security if you have any doubts about statutory benefits.

# Supplementary Benefit

### What is it?

Supplementary Benefit is a payment designed to bring people's income up to a level which the state has decided they—and their dependents—need to live on.

### How do you qualify?

You have to be over 16, living in the UK, and not in full-time work. Payment does not depend on having paid National Insurance contributions, but is linked exclusively to your income and your needs.

### How much do you get?

Payment takes the form of either a Supplementary Allowance or pension, depending on age. The amount depends on individual circumstances. Basically you take the sum of money the government has decided that you, and the people who depend upon you, must have to get by—it's called the scale rate—add on your full rent, or weekly mortgage interest payments, your rates, and any other special allowances. If your income falls below that total you can get Supplementary Benefit. A special long-term rate is payable after two years.

Your income is made up of earnings, other social security benefits and income from savings and capital. But as a general rule the first few pounds earned do not count against payment, if you own your own house its value is ignored, and so is the income from the first £1,200 of any capital you may have. Attendance and Mobility Allowances are ignored completely.

Here's a simple example. A disabled person receives an Invalidity Pension of £19.50. He pays rent and rates of £8 per week. He has a thousand pounds in the bank but no other income. His requirements, as set down in the scale rate are:
£19.90 (weekly allowance)
8.00 (rent and rates)
£27.90
His income is £19.50 (invalidity pension). The money in the bank doesn't count. Therefore he would receive a total income of £27.90 made up of £19.50 (pension) and £8.40 Supplementary Benefit.

### How do you claim?

You can claim on form SB 1 which is available from post offices and social security offices, or simply by writing to your local social security office.

# Supplementary Benefits —Extras

### What are they?

Disabled people may be entitled to extra grants and allowances. They come under two titles, Exceptional Circumstances Additions (ECAs), and Exceptional Needs Payments (ENPs)

### How do you qualify?

The basic rule is that the circumstances and needs must be *exceptional.* The most common ECA is for heating—either because the state of your health means you need extra warmth or the nature of your house makes it expensive to heat. There are others covering diet, laundry, heavy wear and tear on clothing, telephone charges for a housebound person living alone, fares, domestic help and many more besides. ENPs cover such things as clothing and bedding.

### How much do you get?

The payments are not laid down by law. If you have an exceptional cost you should claim for it. The Supplementary Benefits Commission can pay it if it decides the claim is reasonable. However a heating ECA is unlikely to be more than £2.55 per week—more for central heating.

### How do you claim?

Write to your local supplementary benefit office—keeping a copy of the letter—explaining your need. Claim for everything at once and put down the full cost. If you are turned down, appeal immediately to the manager of the local office. The office will automatically reconsider and it may not be necessary to go ahead with a full appeal.

# Housing Grants

### What are they?

Housing Improvement and Intermediate Grants are available to enable disabled people, in privately owned homes, to provide basic amenities and make special adaptations. If you live in a council house or flat responsibility for this rests with your housing department.

### WHAT do they cover?

Improvement grants are paid at the discretion of the local housing authority, usually for the alteration or enlargement of a house or flat. Intermediate grants cover basic amenities like a bath, sink, or toilet, even where these already exist but are inaccessible.

### How much do you get?

The grant is paid to the owner of the house. It is normally fifty per cent of the eligible costs. The owner will have to pay the rest himself but may get some help from the social services or local housing authority.

### How do you apply?

The owner of the property should apply on forms which are available at the local housing office. Grants are discretionary and any appeal must be made, via a councillor, to the local housing committee. Council tenants should approach their housing department.

NB: All social services departments are legally bound to arrange for necessary structural alterations to the home of a disabled person, whether it is council or private property.

# Rent and Rates: rebates, allowances

### *What are they?*

Rent rebates are available for council and new town tenants and rent allowances for private tenants. They are higher for the disabled than the able bodied. Rate rebates are available to all who pay rates. Again they are higher for the disabled than the non-disabled.

### *How do you qualify?*

The rebates or allowances are granted if your income, disregarding any allowed income, falls below the level judged to be necessary for you to cover the cost of living. But people already getting Supplementary Benefit cannot claim a rent rebate or allowance or a rate rebate. You should contact an advice centre, or the local social security office, to see which is best for you.

### *How much do you get?*

It will depend on individual circumstances; on how much your income falls below that which is judged to be necessary for you.

### *How do you claim?*

*Rent:* Application forms and further details can be obtained from your local housing office.
*Rates:* Applications for rate rebates should be sent to the local housing office or borough treasurer's department.

- Under the Rating (Disabled Persons) Act 1978 disabled people will qualify for certain rate reductions from 1 April 1979. An essential facility (toilet, bathroom etc) could be subject to rate relief. Contact your Valuation Officer whose address is in the telephone book under Inland Revenue, District Valuer and Valuation Officer.

# Financing Study or Training

The following are intended as useful hints:

- A 16-year-old mentally or physically handicapped youngster who is still at school can claim Supplementary Benefit in his or her own right. *Contact: local social security office.*
- In addition to the normal grants disabled students may claim a special allowance of up to £180 per year to cover extra costs resulting from their disablement. *Contact: local education authority.*
- The severely handicapped or registered disabled whose prospects of employment are such that they would be unlikely to get a job even if they were not in further education can claim supplementary benefit during term time if they have been refused a grant by their local education authority. *Contact: local social security office.*
- Where parents would be expected to make a contribution to their son's or daughter's grant and are unable, or unwilling, to do so the student can claim, in Supplementary Benefit, the difference between what he or she actually receives and the Supplementary Benefit scale rate. *Contact: local social security office.*
- Financial support and free training is offered by the Manpower Services Commission's Training Services Division in various forms. Details about the Training Opportunities Scheme, TOPS as it is known, are available from Jobcentres, and local employment offices and the Disablement Resettlement Officer will be able to give further information. There was an article on the subject in March/April LINK.
- A number of educational charities, trusts and voluntary organisations offer various forms of assistance. *Contact: ASBAH National Office.*

# The Family Fund

### *What is it?*

The Fund is run by the Joseph Rowntree Memorial Trust and the money is put up by the government. Its job is to help families caring for a severely handicapped child under the age of 16.

### *Do you qualify?*

Any family caring for a severely handicapped child may apply for help.

### *What kind of help?*

The Fund is designed to complement the help available from your local authority. There's no set list, so ask for what you need. The most common form of assistance so far has concerned family holidays, driving lessons, car hire etc—and laundry-washing machines etc.

### *How do you apply?*

Simply write to the Family Fund, Beverley House, Shipton Road, York, Y03 6RB and ask for an application form. After you have returned the form one of the Fund's social workers will then call to discuss your claim in more detail.

# Other Forms of Help

- Prescription Charges: Some people may be exempt, or entitled to a reduced rate. They will include people on Supplementary Benefit and those whose income is not much above it. *Contact: local social security office.*

- Hospital fares: If your income is low and your child has to attend hospital regularly, or you have to visit him in hospital, you may be able to get help with the fares. *Contact: the hospital social worker.*

- Free Milk: If your handicapped child is of school age but cannot attend school, you can get free milk for him. *Contact: local social security office.*

ASBAH's Spring Conference was attended by 165 delegates—professionals, parents, and young people with spina bifida and hydrocephalus—all of whom gathered together at Bath University to hear various speakers on the subject, "A Life to be Lived".

The Conference, once again, was fortunate to have as its hostess, the Lady Jean Mackenzie, and the Joint Chairmen were Sir George Haynes, CBE, Vice President of ASBAH, and Professor Neville Butler, MD,FRCP, DCH, Professor of Child Health at the neighbouring University of Bristol.

Sir George, in his opening speech, said that the social history of our country had been moulded largely by the stirling efforts of voluntary organisations like ASBAH.

Professor Butler spoke of the present situation of those with spina bifida in this country and the quality of their lives, and the problems faced by them and their families. The full text of his speech will be carried in the next LINK.

# Leisure

LEISURE activities—planning, developing and expanding the choice available—were discussed by four different speakers.

**Miss A. Buchan,** Superintendent Physiotherapist at the Frenchay Hospital, Bristol, spoke of the task of preparing young disabled people for leisure. She said there was a tremendous amount that physiotherapists and special units could do in this field, but, as always, it was a question of people speaking up and saying what they wanted. He who shouted loudest was listened to.

**Mrs E. Gutteridge** gave an example of an increasingly popular leisure occupation—handcrafts. Mrs Gutteridge, of the Handcrafts Advisory Association for the Disabled, pointed out that most disabled people took up craft work out of a desire to be creative, rather than for financial gain. She said anyone who would like to see examples of craft work by disabled people was welcome to visit the Friends' Meeting House, Euston, London on June 7, 8 between 10.30 am-4.30 pm. 1,400 entries in the National Craft Competition would be on display.

**Mr M. Lazell,** Deputy Warden of the Churchtown Farm Field Studies Centre, near Bodmin Cornwall, said family groups, schools, individuals—all were welcome to have a go at all kinds of leisure pursuits—canoeing, sailing, fishing, rock-climbing, rural and field studies, indoor leisure activities, to name just a few. The Centre is run by the Spastics Society. Mr Lazell said that one of the aims was to enable the disabled to experience new things. "We can get you to places where you wouldn't think a wheelchair could get—tops of cliffs, rocky shores, fields . . ." he said.

**Mr B. Perfect,** Manager of Faseman House Day Centre, Coventry, spoke of leisure activities in relation to the daily lives of those at the centre. He said that apart from more traditional pursuits, the residents were encouraged to learn how to cook, and how to cope with shopping as first steps to independence and rehabilitation. There were also educational courses—maths, and english were important. Jobs such as filling in forms for grants, or employment could be explained. Residents were introduced to the world of work through various work experience projects such as letterpress printing, and electrical component assembly.

DAPHNE KENNARD, Musical Adviser to the Disabled Living Foundation, was an admirable choice as the first speaker of the Conference. In no time at all she had the audience singing together, and doing exercises to music, as she demonstrated some of the tremendous benefits that music can bring to everyone's life.

The particular importance of music for the disabled is that it can enable them to be independent, and she listed a considerable number of musical instruments that could be played from a wheelchair.

Music enables one to be part of a team, and she was concerned that young people, after leaving school, should make efforts to join some kind of musical gathering—a folk club, church choir, musical appreciation society, pop group, or whatever.

Miss Kennard explained that music can channel one's frustrations in a socially acceptable way. Through music one can express feelings more easily than by talking. It can help us to understand each other, it aids concentration, and can stimulate discussion and develop intellectual understanding. Even though one may be in a wheelchair one can respond rhythmically to music by using other parts of the body such as arms and hands.

# Occupation and employment

UNDER THE heading, Occupation and Employment, Miss Jenny Hume, Senior Careers Officer of the Spastics Society warned that the considerable increase in facilities available for disabled school leavers presented problems when it came to selecting the right path.

School staff and local authority careers officers were often unware of the full range of further educational and training opportunities available where the young person lived. Some had a limited or unrealistic view of how the pupil would fit into the world beyond school.

She felt that proper assessment—carried out away from the school situation (but in consultation with staff and parents)—was the signpost to the road ahead, and she was pleased that local assessment facilities were developing.

**Mr E. Medlock,** Deputy Area Resettlement Adviser, working for the Employment Services Division, said that, in his experience, disabled people desperately wanted to work. "Their biggest aim is to be accepted as normal members of the community and that includes the working community".

He said that there were 150,000 disabled unemployed, of whom about one-third would probably never work—not because of lack of opportunities but because of lack of drive and determination, and because they may have lost their motivation. We must all take a share of blame for this said Mr Medlock. Disabled people needed back-up and encouragement from parents, good education and realistic assessment.

"There is a need to be realistic. I have seen too many people with their hopes built up, but only to be dashed later on".

The Employment Services Division existed to give support to disabled workers and had a whole host of facilities. It was essential, he said, for the disabled person to pursue and cultivate a good relationship with the Disabled Resettlement Officer.

Mr Medlock also referred to other help available—the Fares to Work Scheme (usually up to £25 a week, but more in exceptional cases), and the provision of special aids in work (perhaps a typewriter or special desk), and the adaptation of premises.

**Mr Charles Pocock** gave a dynamic talk about the work of Remploy of which he is Information Services Manager.

Remploy was set up in 1944 under the Disabled Persons Act and now has 84 factories, in England, Scotland and Wales, employing 8,200 disabled people.

"They are all contributing to a sales turnover of £29-£30 million each year".

He said "If it's very good, it's made by Remploy", and gave examples of some of their products—knitwear for Marks and Spencer, the Goodwood Ash range of very expensive furniture exclusive to Heals, protective suits for the American Air Force, orthopaedic aids and appliances for the National Health Service, and recently a £3½ million furniture contract for Saudi Arabia.

He explained that workers were taken fron Section 2 of the Disabled Persons' Register, and must have 'a desire to work'. So long as a disabled person can complete a job in one hour that would take an able-bodied person 20 minutes then he was suitable for Remploy.

"That doesn't mean that all our workers do a 20 minute hour" said Mr Pocock, "Some of them do an 80 minute hour!"

They are paid a basic wage, are members of Trade Unions and the factories also have Joint Consultative Committees so everyone can have a say in the running of the business.

Sailing at Churchtown Farm Field Studies' Centre

# Accommodation

THE ROLE OF Local Authorities: Mr D. Morris, MEHA, ARSH, of the Environmental Health Department of Tewkesbury Borough Council, detailed legislation which imposes duties on local authorities with regard to housing, and he spoke of the sometimes "complicated and frustrating business of getting money from the welfare state—money which is, quite rightly, available to assist disabled people to live in their own homes".

He also pointed out that recently local housing authorities (and housing associations) and social service authorities had been asked to adopt a more positive approach to adapting houses for disabled people speedily and effectively.

THE CHANGING role of one voluntary organisation: Mrs G. Corney, Counsellor for the Cheshire Home Foundation said that there was a growing variety of housing available for the disabled. The Foundation had recently formed its own housing association to provide individual units for the disabled and their families. It was involved with a pilot domiciliary care scheme (similar to the Crossroads Scheme) in the Liphook area of Hampshire, where trained people will give practical help to the disabled in their own homes. If successful the scheme would be developed by the Foundation in other areas. Mrs Corney said if anyone in the Liphook area would benefit from this kind of care, Mrs Mary Hopcroft organiser of the scheme would be pleased to hear from them.

# Services

**Mrs M West** of Avon County Council pointed out the confusion and bureaucracy that exists in trying to co-ordinate the work of the social services, DHSS, education, housing and life.

She said that her work as an adviser to a Social Services Department was sometimes made more difficult by the 'stiff upper lip' attitude of many parents and handicapped people who manage until crisis point and then wonder why no service is available.

Mrs West also emphasised the strength and influence of local voluntary pressures and initiatives on statutory provision.

**Mrs Hilary Gatfield** is an example of how one person can have considerable influence. She spoke of the way in which she had been able to work with Downs Surgical over the last seven years to set up a nationwide nursing service to advise on fitting of appliances for the disabled.

She made the point that the nurses at Downs have a wide knowledge of spina bifida, and that they will advise with the fittings of many different appliances and not just those supplied by Downs. The appliances are available under the National Health Service. Downs now have a London showroom where it is easy for the disabled to call for personal advice and fittings and the nurses are also available to help all over the country. (See advertisement on page 8).

**Dr Adrian Stokes** is a member of ASBAH's Executive, as well as being concerned with Motability and the Jubilee Access Committee. He had little trouble in holding the attention of his audience.

In speaking about Motability he was able to announce that a new Hire Purchase Scheme to enable the disabled to buy a new car has been launched. The rate at present is a flat 9 per cent and initially the scheme will be phased in for 56 and 57 year-olds and then gradually extended.

He also welcome the introduction of a new committee, CORAD—(the Committee on Restrictions Against Disabled People) which will consolidate and carry forward—particularly at local level—the gains which the Silver Jubilee Committee on Access were able to make. More details in future LINKs.

## Ethics

*ON THE Saturday evening there was a discussion on 'Ethical Matters of Concern' led by the Rev. Preb. R. Lankester, BA., Chaplin of Bath University, and Dr Sam Weller, Consultant Paediatrician.*

Mr Lankester said that fresh ethical decisions had continually to be made in the light of technological advances in the medical field.

Dr Weller spoke of the problems of antenatal screening which can detect many cases of spina bifida, but with some risk to the foetus, and if bought in on a national scale for all pregnant women, it might lead to the loss of normal as well as handicapped babies.

The discussion mainly centred on the sensitive problem of the selection for operation of newly born babies with spina bifida. It was a painful decision that has to be made within a few days of birth—although not on the first day as used to be the case.

Parents are obviously not in any fit state to make a clear decision, and there was a suggestion from the audience that it might be an idea to enlist the aid of parents of older spina bifida children. If properly counselled and trained such parents could be available to talk to and counsel new parents.

The discussion seemed to come down on the side of allowing all spina bifida babies to have treatment and the proper chance of life, but it was appreciated that those at the Conference were 'biased' being parents of older spina bifida children, and professionals who know, love and are used to working with such children.

## Points

*THESE ARE some of the main points that arose out of the individual group discussions—not least was the need for much more time for discussion at future Conferences.*

- Parents were anxious about the future of their children when they are no longer able to look after them. Schemes were discussed to enable young people to gradually move away from home. Could ASBAH build hostels of its own?
- Local pressure groups are very important, particularly in relation to access.
- ASBAH doesn't have as strong a public voice or image as some other bodies, and must also be keeping abreast of the development of silicone chips so that our young people get an equal deal in any future society.
- Could the Fares to Work Scheme be extended to cover fares to sheltered workshops and fares to day centres?
- Disabled young people have an equal right to work as the able-bodied.
- There appears to be great discrepancies between what statutory authorities are able to provide and what is actually available. There was general dis-satisfaction about the effectiveness of the Disablement Resettlement Officers.
- More attention must be given to the *severely* disabled spina bifida and hydrocephalic young people.
- A disablement income would enhance the natural dignity of the individual.

## About ASBAH

**I HOPE this article will be the first of a regular series to keep readers of LINK more informed of the work of ASBAH. Future articles will contain reports from Council Meetings and Executive Meetings, as well as covering activities and projects on which national officers are working**

This issue of LINK is concerned with the Spring Conference which was held at Bath University. I think it might be appropriate that this first article complements the fuller report. Perhaps it should be called "The Right to Reply"! I asked all delegates to complete a questionnaire about this Conference to glean ideas for the future. There has not been time to analyse the replies but this is under way and we will be reporting in a future LINK. Some of the discussion groups, however, took the format of this year's Conference as a topic and I would like to comment on one or two of the points which were reported back to the final session.

First, there seems to be some misunderstanding about ASBAH's relationship with the media. We all appreciate the need to make ASBAH's name and work better known, and take every opportunity to do this. However, we must say that there is no possibility, at the moment, of ASBAH's buying space to make us well known because we simply do not have the financial resources to do this. As far as other press, radio or television cover is concerned, no matter how many hours we spend talking to journalists and reporters, there is no way that we can guarantee that the interviews will be published. In the last few months national officers have been interviewed by journalists and reporters from local and national newspapers and television and radio. Our press cuttings prove that sometimes interviews are published and sometimes not. Nevertheless, we think that talking to the media must be helpful; and we are increasingly being consulted by them.

I think that probably all national staff and particularly Mrs Newman, Miss Vernon and Miss Tomlinson were disappointed to learn that delegates still think that hydrocephalus is low on our list of priorities. It is true to say that the research project which, with the co-operation of the staff, has already started at Banstead Place, and the one at Derwen College planned for the very near future are both primarily concerned with problems faced by adolescent and young adult hydrocephalics. Additionally the greater part of the emphasis at Independence Training Courses is directed toward trying to overcome problems of concentration, retention of information, co-ordination and spatial unawareness that are presented by young people with hydrocephalus. We know many of the problems which spina bifida causes. We are still trying to evaluate the problems of hydrocephalus.

The last point on which I would like to comment is the age limit imposed on delegates this year. Some of the discussion groups thought that it should be 16 rather than 18. The decision of 18 years was reached after a great deal of heart-searching and with considerable disappointment. It was, however, as a direct result of our experiences at the 1978 Spring Conference when, of the 40 or so young people who attended in wheelchairs, more than 15 were in need of more physical attention than the staff could possibly give them. I honestly think that one of the reasons that this year's Conference was by general acclaim one of the most successful so far held, was that everyone who attended was adult in attitude, had physical problems under control, and was therefore able both to contribute to the Conference and to benefit from it to a much greater degree. This is not to say that younger people do not have their own contribution to make and we are exploring the possibilities of LIFT conferences. It was also, I think, the reason that this year, for the first time, every discussion group would have liked more time and has asked for this to be allocated in the future.

Moyna P. Gilbertson

## Tell us what you think about Conferences

**ANNUAL Spring Conferences take a great deal of organizing. If the membership finds them interesting, helpful and enjoyable, they will continue.**

**Over and over again this year, speakers emphasised the need for individuals to make their needs known. National staff echo that request.**

**With the next Bulletin there will be a questionnaire for those who did not attend this year's Conference, or who have never attended a Conference.**

**We are most anxious that Conferences be supported by all Local Associations. We want to know why it is that only about 20 are ever represented at Conferences.**

**Please help us by consulting with your local Associations and friends, and returning the questionnaire to us so that we can give you the service that you want.**

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## THE CHAIR DESIGNED SPECIFICALLY FOR THE SPINA BIFIDA CHILD

Careful research into the special problems of the Spina Bifida child resulted in the Newton Yorkhill – a light, compact chair for 2–6 year-olds.

The Yorkhill is easily self-propelled by a small child. Or the foot-operated prop stand will hold it firmly parked – and with the adjustable moulded tray fitted, it's a safe base for meal times or play.

The versatile Yorkhill folds for transport – has an adjustable footboard – a cushion extension for use with calipers – and a safety bar for head protection. In padded P.V.C. upholstery with the frame in chrome or red enamel.

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# If you're 60 or under and severely disabled, claim Mobility Allowance now.

If you are aged 60 or under (i.e. if you were born after 6 June 1918) you should claim Mobility Allowance now.

Claims can also be made for children aged 5 or over.

This is a benefit to help severely disabled people who are unable (or almost unable) to walk.

It is up to you how you use the Mobility Allowance to help you get about. The allowance is worth £10-a-week.

Fill in the coupon so that we can send you leaflet NI.211 which includes a claim form and tells you more about the scheme. Or you can ask at your local Social Security office.

**Claim now for anyone aged 5-60.**

To: Mobility Allowance Unit, DHSS, Norcross, Blackpool FY5 3TA.
Please send me a copy of leaflet NI.211 about Mobility Allowance.

Name (Mr/Mrs/Miss)____________ Age____

Address____________

____________ Postcode______

Remember only claims for those aged 5-60 can be accepted now. Others under age 65 will qualify later.

Issued by the Department of Health and Social Security.

# Time to do something about those Christmas cards

IT SEEMS a little strange when we are only just getting over the snows of this exceptionally bad winter and while we are all looking forward to better things in the summer, to start mentioning Christmas cards! However, as you no doubt know, these things have to be put in hand very early and we at National ASBAH have recently made a selection of cards for our 1979 range.

This year we have tended to go slightly more "up-market" as various people commented that they were not pleased with the selection last year and we do hope that our choice may meet with your approval.

I know that Webb Ivory offer an excellent service and that many of you avail yourselves of it, but do hope that you might be prepared to give "supporting home industry" a trial.

One of the problems that I understand has affected your decisions in the past is the fact that you have to buy the actual cards from us and produce the stock for sale at fund raising events. I can appreciate the difficulties involved in this and wonder if you might like to run a Christmas card campaign in the same way we do in the office.

This would involve you in placing an order for the number of illustrated Christmas card leaflets which you feel you could distribute and then over-stamping them with the name of your Local Association.

All you would then have to do is circulate the leaflets and ask your potential buyers to fill in the order form and send it directly to Dixons. Dixons would then despatch the cards direct to the buyer (they really are very efficient) and all that would then remain would be for you to wait to receive a cheque from us in the New Year crediting you with the full profit on orders received bearing your Association's name.

The profit margin on our cards is 40 per cent which I am sure you will appreciate would show a much larger return to your kitty than commercial companies could possibly offer.

If you are interested in participating I should be most grateful if you could let me know, provisionally, as soon as possible, your approximate requirements as we shall have to reflect your wishes when we place our brochure order.

I KNOW that you like to be able to recognise members of ASBAH's national staff and for that reason, following the publication of head office personnel's photographs in the January edition of LINK, I am now following suit by including pictures of the three recently recruited members of the fund raising staff.

Madeleine Legg

Barry J. Mishon

Jane Evans

# Partnerships pays the best dividends

You have already heard of Mr Barry Mishon and his splendid literary dinner that was held in Brighton on March 29 and Madeleine in Surrey/Hants/Berks together with Jane in the Midlands area, are also making every effort to promote new and exciting fund raising events to compete for funds with all other charities.

I know that a lot of Local Associations are worried that Head Office fund raising may be detrimental to their own activities, but I do promise you that Barry, Jane, Madeleine and myself are all most careful to liaise with Local Associations and to find areas of revenue which are not already being tapped.

I know that we would all prefer that contributions to charity should come to ASBAH, whether national or local, than to find their way into the coffers of other charities, no matter how deserving, and it is for this reason that I ask you, again to consider the possibility of allowing us to find additional sources of funds in your area which will most certainly benefit you whether directly or indirectly.

In the long term I am sure that this is the only way in which ASBAH can survive and I do appeal for your co-operation and comments.

**JUDY KAY**
**Director of Appeals**

# CLASSIFIED 'ADS'

**Adverts for next LINK must be in by June 1. The address is: LINK Advertising, ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ.**

**Rate: £1.00 for up to 25 words. £2.00 for 25–40 words, £3.00 for 40–60 words. Please send remittance with your advert. You may like to pay for a whole year's advertising in one go.**

**HOLIDAY ACCOMMODATION**

**CAMBER SANDS:** Well-equipped and adapted chalet (sleeps 6). Bookings taken from January by Mrs J. Wilson, 23 Sunnydale Gardens, London NW7. Tel: 01-959 2962.

**WINTERTON-ON-SEA,** Nr Gt Yarmouth: 6-berth chalet, indoor swimming pool, shop, play areas. Details: Mr R. Morris. Tel: High Wycombe 32184.

**PRESTATYN:** 6 berth caravan, accessible all amenities. Special reduced rates out of season. Details: Mrs E. Taplin, Colonial House, 63 Corporation Street, Manchester M4 3DT.

**MABLETHORPE,** Lincs: Two well-equipped chalets, self-contained, 6-berths, at Mablethorpe Chalet Park, Links Road, Mablethorpe. Details: Mr. B. Guest, 57 Bloxwich Lane, Walsall.

**MILLENDREATH,** Cornwall: Well-equipped chalet, sleeps six. Easy access. Details (s.a.e. please): Mr. C. Matthews, 11 Kingsbere Avenue, Ensbury Park, Bournemouth, BH10 4DL.

**WESTGATE ON SEA:** Semi-detached holiday bungalow, sleeps 6/8. Bath hoist, garden, 10 mins walk sandy beaches. Details: Jean Jones 01-467 8148. Greenwich ASBAH.

**GOLDEN SANDS, VORYD, RHYL,** N. Wales: 8-berth caravan. Mains water, electricity, gas, shower, television. Every facility on site, right by sea. Details: Mr S. Foster, 84 Elmwood Drive, Blythe Bridge, Stoke-on-Trent. S.a.e. please.

**WESTWARD HO,** North Devon: Chalet Bungalow for 6 people. Excellent site facilities. S.a.e.: Mrs Cattell, 1 Rushwood Close, Mellish Road, Walsall, West Midlands.

**FOR SALE**

**Leisure Wear:** White cotton **Tee Shirts** with green Family symbol and words 'Support Spina Bifida' £1.60 each size 22"–30", £1.85 each small, medium, large. Also quality **Sweat Shirts** with reverse colours in all sizes including extra large adults. All at £4.50 each plus postage. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks. For Bucks/East Berks ASBAH.

**Batric wheelchair:** 3 year old. Two batteries (one year old). £300 o.n.o. Write to : Jeremy Mather, 25 Firswood Mount, Gatley, Cheshire.

**SERVICES**

**THE DISTRICT** Advertising Company of EMI Elstree Studios, Shenley Rd, Borehamwood, Herts. WD6 1JG, offer a special service to charities. They produce telephone, address and notebooks free of charge, for fetes, bazaars and other events; fund-raising charts, with pockets for donations, which also help recruit membership and promote your cause, and are displayed in public houses, restaurants, on factory noticeboards and other prominent places; programmes for fetes, donkey derbys, bazaars and football matches etc. Calendars and Diaries can also be obtained, all free of charge. For further information contact Mr J. A. Alter, at the above address or tel: 01-953 1600 ext. 171.

## *The Spina Bifida Baby*

THE EAGERLY awaited revised edition of this booklet by Mrs Olwen Nettles is now available. Orders of up to five copies can be supplied by National ASBAH in London. Larger orders may be obtained from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BN. Price 30p per copy plus 9p postage and packing.

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# ASBAH booklets etc . . .

| | |
|---|---|
| *Your Child with Spina Bifida,* by J. Lorber, MD, FRCP | 25p |
| *Your Child with Hydrocephalus,* by J. Lorber, MD, FRCP | 20p |
| *The Nursery Years,* by S. Haskell, MA, Ph.D, and M. E. Paul, Dip.Ph.H | 15p |
| *Children with Spina Bifida at School,* Ed. P. Henderson, CB, MD, DPH | 30p |
| *The Care of an Ileal Conduit and Urinary Appliances,* by E. Durham Smith, MD, MS, FRACS, FACS, and others | 15p |
| *Clothing for the Spina Bifida Child,* by Barbara Webster, SRN, RSCN | 15p |
| *Aids and Equipment* | 60p |
| *Sex and Spina Bifida* by Bill Stewart (75p to LIFT members). | £1 |
| Information leaflets | 100 for £1.30 |

All available from ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 9p per booklet.

**Scottish Spina Bifida Association Booklets**

| | |
|---|---|
| *Growing up with Spina Bifida* | *30p* |
| *The Spina Bifida Baby* | 30p |

both by O. R. Nettles, McSP, ONC.

Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

**FUND RAISING AND PUBLICITY MATERIAL**

**Posters**

| | |
|---|---|
| **Best Foot Forward 20 × 30 in.** | **10p each** |
| **Best Foot Forward 15 × 10 in.** | **10 for 40p** |
| **For local publicity 15 × 10 in.** | **10 for 40p** |
| **Car Stickers** | **2p each** |
| **Plastic Lapel Badges** | **3p each** |

**All available from Appeals Dept.**—postage extra.

**The Appeals Dept. carries a range of fund-raising items, i.e. pens, balloons, calendars, tabards, car stickers. Send for list and order form.**

**Flag Day equipment** can be obtained direct from: Angal, 48a Holmbush Rd, London SW15 3LE (01-788 5464).

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