

# LINK



Association for Spina Bifida and Hydrocephalus/ASBAH 10p

Sept/Oct 79



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# Link<sup>64</sup>

Association for Spina Bifida  
and Hydrocephalus/ASBAH

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A NEW government. A new view of economic reality. And a number of possible implications for the disabled.

Speaking at the annual meeting of the Royal National Institute for the Blind in July, Mr Reg Prentice, the Minister for the Disabled, outlined his view of the effects of government spending cuts on disabled people. He said: "I hope that cuts in services for disabled people will be few and far between, but it would be foolish to pretend that they will not be affected. Existing cash benefits from the government — such as Invalidity Pensions, Attendance Allowances and Mobility Allowances — will be maintained . . . Local authorities will, I hope, strive to find other areas for economies before reducing their services to the disabled and the chronically sick". "But it is equally clear that we cannot take new initiatives in the near future if they would cost money".

Mr Prentice will be developing the theme in a special article he has agreed to write for the next issue of LINK. Don't miss it.

### *Warm praise and practical help for SPOD*

MRS LYNDA Chalker, Parliamentary Secretary at the Department of Health and Social Security has praised the work of SPOD — the Committee on Sexual Problems of the Disabled.

She told a SPOD International Conference: "You have declared on behalf of all disabled people the right to the warm and loving relationships which the able bodied have always taken for granted".

And as evidence of the government's favourable opinion she announced a grant of more than £25,000 to help expand the work.

### *Simplicity — at a price*

MONEY — this time the need to spend it — was also on the mind of Professor David Donnison, the Chairman of the Supplementary Benefits Commission, when he announced the Commission's response to a review of Social Assistance in Britain.

He said: "It will be impossible to maintain acceptable standards of service for people in Britain who are in real need unless something is done to simplify supplementary benefits and other increasingly complicated schemes on which they depend".

Then the sting. "That cannot be done satisfactorily unless the government is prepared to spend some money to put things right. We hope they will act swiftly; the need is urgent".

### *Temporarily off the road*

MOTABILITY, the organisation which leases specially modified cars to the disabled was temporarily off the road in June — put there by the impact of higher Value Added Tax announced in the budget. The organisation pays VAT twice, first on the purchase price of the vehicle and again when it is leased to a disabled driver. It was just too much and Motability stopped trading.

But it's good to be able to record that relief arrived with all the speed of an efficient breakdown service. The government answered Motability's request for help by allowing it to reclaim the VAT on the purchase price. Motability was back in business.

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**COVER STORY: Nurse and patient share a moment of happiness. Georgina Deere of Knowle, Solihull, laughs with Staff Nurse Catherine Bardsley who has helped to make her stay at Birmingham Children's Hospital a happy one. Photo: Birmingham Evening Mail.**

## 'They're not different'

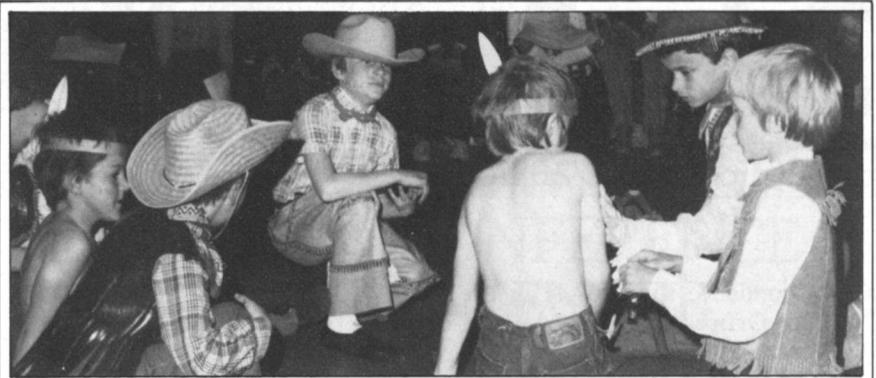
SUSSEX Association which helped to pioneer ASBAH Independence Weeks — now called Social Rehabilitation — three years ago, again held an Independence week for Sussex teenagers at Felbury House, near Camberley, Surrey in the Summer.

Twelve teenagers with spina bifida and ten able-bodied youngsters shared the experiences of the week. It included a wide range of tasks, talks, advice, practical sessions and social outings.

Some of the young helpers comments included: "It was not half as bad as we'd thought. How the nurse explained it, it sounded terrible, but it wasn't. This was the first time we'd worked with handicapped children and we thought they'd be different, but they aren't".

□ □ □

SUSSEX youngsters were out and about again later in the Summer, in August, when a group experienced the thrills and spills of rock-climbing, dry slope ski-ing, and canoeing with the help of staff from the Bowles Centre at Eridge, near Crowborough in Sussex. The staff at Bowles also supervised a day's sailing at Bewl Valley reservoir near Lamberhurst.



A cowboy sketch performed during a Display Evening by the 1st Eastham Boys' Brigade Company, in the Wirral. The cowboy (centreback) is 11-year-old Jeffrey Newall . . .

AND HERE IS a letter from LINK reader Mrs Newall of Eastham Merseyside about her son.

Jeffrey has hydrocephalus and is also registered blind so it was with a feeling of great pride that we watched him receive his Gold Award during the Annual Boys' Brigade Display Evening.

Jeffrey is a member of the 1st Eastham Boys' Brigade Company and the Gold Award is the highest award any boy can receive whilst in the Junior Section. The Award is gained for work done in four sections — physical, spiritual, educational and social — so it goes without saying that, because of his sight difficulties, Jeffrey had to put twice as much effort into everything he did to gain the award.

## Progress in Northern Ireland

IN 1974 The Northern Ireland Association for Spina Bifida and Hydrocephalus gave evidence to a government working party considering the prosthetic<sup>(1)</sup> and Orthotic services in the Province. They pressed for improvements in the provision of appliances and the creation of a workshop.

In 1975 the report was published, and as a result considerable changes are in progress. A new Rehabilitation Unit (Engineering) has been built at Musgrave Park Hospital, where the disabled who have special problems can be seen, and the unit can create appliances and aids where these are not available from the state or commercial sources.

The unit carries out research and also has an educational programme to improve the knowledge of prosthetics, orthotics, and aids. Staffing includes an orthopaedic surgeon, a bio-engineer, and five trained orthotists who have been qualified at the University of Strathclyde.

The Rehabilitation Unit (Engineering) is part of a larger scheme to integrate the provision of artificial limbs, appliances, and aids into a prosthetics/orthotics aids service. This will include the provision of an Aida demonstration unit. The Northern Ireland Association has bought some of the equipment not supplied by the government and keeps in close contact with the staff at this new Unit.

<sup>(1)</sup> A Prosthesis is an artificial replacement, eg an artificial leg.



Members of Hull and District Association on holiday in Holland this year.

THE LAST trip to the continent organised by the Hull association proved so popular that 35 people — spina bifida members, parents and friends got together this year. The five day trip included a chair lift ride in Belgium, in the Ambleve valley, a boat trip on the Rhine, as

well as enjoying the pleasures of Valkenberg.

One tip to others travelling with wheelchairs comes from Hull's Secretary — Mrs Gerritje Brown — be sure to take a puncture outfit and spare inner tube with you!

# About ASBAH

## Research

I ATTENDED the Newcastle meeting of the Society for Research into Hydrocephalus and Spina Bifida and presented a paper on Independence Training, which had been prepared jointly by Barbara, Jill, Jan and me. This aroused interest in the work of ASBAH and we are very pleased that Dr Keen, consultant paediatrician in Manchester, has approached us to organise a week in his area next year. An article based on this paper appears on pages 10-12.

## Friendship Group

ASBAH took a very active part in this year's Conference of The Friendship Group of Charities. The subject was "Communication — a Key to Living" and more than 200 people attended, some of them from overseas. The Charities forming the Friendship Group are ASBAH, The Lady Hoare Trust for Physically Disabled Children,

The Invalid Children's Aid Association, The National Association for the Welfare of Children in Hospital, The National Society for Autistic Children, The National Society for Mentally Handicapped Children, The Shaftesbury Society and The Spastics Society, who came together some years ago in an effort to make their work more widely known.

## Royal Garden Party

IN JULY Mr and Mrs Armour and Carole, Alan and Margaret Twyford, Mr Tallamy and I were privileged to represent ASBAH at a Royal Garden Party. Alan, Margaret, Mr Tallamy and I were additionally honoured to be presented to HM Queen Elizabeth, the Queen Mother. It was altogether a memorable occasion.

## Films

MANY OF you will have seen the film, *Growing Together*. There is a

great need for short films and so we have extracted parts of the full length feature and hope that we have produced a useful film which can be used to explain some of the general aims of ASBAH and also for fund-raising purposes. It will be available in both conventional film form and as a cassette.

## Executive Committee

FOLLOWING the Council Meeting which was reported in the last issue, I am sure it will come as no surprise to readers to know that ASBAH's financial situation was discussed in detail at the Executive Committee meeting in June. A Steering Committee was formed to advise on the current position and will put recommendations to Executive.

*Yvonne P. Gilbertson*

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## ASBAH NEEDS HELP TO FIND A SIGN OF THE TIMES

IT HAS been agreed that ASBAH should try and find a new logo or symbol that would reflect its identity and its work today. So far no-one has come up with anything suitable.

LINK readers are invited to give the idea some thought and see if they can design a simple, modern, evocative and eye-catching logo that would take ASBAH into the '80's.

It would replace the present figure of father, mother and child. The general feeling is that this is no longer entirely appropriate as the emphasis today is much more on meeting the needs of members as they grow up through their teens and into adult life.

ASBAH is not looking for finished or polished designs — just the germ of a good idea, so don't worry how rough and ready your presentation is.

So let ASBAH have any ideas. It is not always the professionals that have the best ideas — often a simple, straightforward suggestion from an amateur is equally effective.

Send your ideas to Pat Silverthorne at National Office.

## CORAD and discrimination

**A NEW committee is now looking into the whole question of discrimination against disabled people in Britain. It's called the Committee on Restrictions Against Disabled People and it has arisen out of the Jubilee Committee on Access. The Chairman is Mr Peter Large MBE.**

When it began its work earlier in the year Mr Large said: "Somehow we have to devise a means of preventing society riding roughshod over the rights of disabled people. Whether this requires the club or the carrot, education, exhortation, or legislation remains to be seen . . ."

Mr Large said:

- Nobody intended fire and safety precautions to prevent disabled people from working or studying or enjoying themselves. But that is

exactly what they are doing.

- Nobody intends Codes of Practice covering fire precautions to prevent disabled people from working or shopping or living in certain places. But that is exactly what will happen if steps are not taken to call a halt to what I regard as an insane quest for unobtainable ultimate safety . . .

- When parking meters, traffic wardens, yellow lines and pedestrian schemes were invented, nobody intended them to stop disabled people working, shopping or enjoying themselves in certain places. But that is exactly what they are doing in central London and elsewhere.

The Committee is expected to call for evidence on particular areas of concern, soon.

## New appointments

□ Congratulations to Professor Michael Laurence on his election as President of the Society for Research into Hydrocephalus and Spina Bifida. Professor Laurence is Professor of paediatrics at the Welsh National School of Medicine, at the University of Wales.

□ Congratulations, too, to Miss Moyna Gilbertson, ASBAH's Chief Executive Officer who was recently elected to the Executive Committee of the Society.

## Achievement award opens out

TO MARK the International Year of the Child, the Spastics Society has decided to open its 1979 Achievement of the Year Award to children suffering from any type of handicap. Candidates, aged 5-16 years living in the British Isles are eligible.

The citation is 'for the bravest or most outstanding effort or achievement in any field by children who have been handicapped since birth, or who have suffered handicap by the age of five years'.

Lesser achievements, which have nevertheless demanded great effort and determination, or disabilities borne with courage and cheerfulness, stand as much chance as winning as more spectacular feats. The judges take into account the degree of handicap.

First prize is £250 and a silver cup which the winner keeps. Second prize is £50, third prize £25. All finalists receive an inscribed medal and will be invited, with escorts, to a celebration lunch in London and the Award ceremony.

Anyone who knows a handicapped child who they think deserves to be considered for the award can put forward a nomination. This is done by writing to the organiser, Mrs Nina Heycock, giving full details of the child, background and achievements. Letters should be typed if possible. Parents of every nominee put on the eventual short list will be written to for permission for the child's name to go forward.

Nominations are welcome from now until December 1. The address is: Mrs Nina Heycock, 27/33 Harrington Gardens, London SW7.

## Switch to day conferences

**AT THIS year's ASBAH Spring Conference those attending were asked for their comments about future Conferences. The general feeling was that members would prefer a series of Day Conferences as a change from the one main get-together, and as a result there will be no Spring Conference in 1980.**

**Day regional conferences, particularly geared towards**

**young people, will be held. There will probably be four — two in London and two elsewhere — and additionally it is hoped to hold a Conference for professionals concerned with services for spina bifida and hydrocephalus, in co-operation with GLAD (the Greater London Association for the Disabled). More information in a later LINK.**

DURING the Saturday evening discussion at the ASBAH Annual Conference I had thoughts in my mind which the strength of feelings in my heart prevented me from expressing coherently. I decided it might be helpful to put some of them in writing to share them with others.

It was good to hear, and see, so many young ASBAH members testifying to their joy in living. No-one would dream of disputing their right to survival. They were the lucky ones; well endowed with the power to live and grow. They had been lovingly and successfully cared for, and treated, during their early years.

We all of us know of others who are less fortunate. Alas, we are still far from being able to guarantee one hundred per cent success in the treatment of hydrocephalus. Progressive scoliosis can be a painfully crippling condition. While the majority of girls can find satisfaction in the possibility of having babies, far fewer boys and girls can look forward to a very satisfactory sex life. Of course no physical handicap need cripple a person's joy in living. But a person with multiple handicaps certainly needs to be exceptionally well endowed, both in personal strength and in the quality of care he receives.

The most unfortunate, a child who is severely mentally as well as physically handicapped, can at times present an intolerable burden to his family. Even the best parents can find themselves failing among the competing demands of a multiple handicapped child and the needs of the family as a whole. Small wonder that some doctors feel that babies who seem pretty

## Is death the worst thing that can happen?

certain to be multiple handicapped should be left for nature to take its course. Small wonder that, when such children die, we often say 'it was a merciful release'.

I sometimes wonder if death is really the worst thing that can happen—even to a child. I have worked in Africa for long enough to experience conditions in which childhood death is almost commonplace. As a child, I grew up in the security of my Victorian grandparents who looked forward cheerfully to a holy death. Every night we sang 'teach me to live, that I may dread, the grave as little as my bed'. When children died, they were 'taken to Jesus'. Eternity was peopled with babies and children, as well as by the old.

Any parent who has lost a child will wonder about this. Which of the seven ages of man is the really eternal bit—or how is it all transformed? And if a little seed of life has really no chance in a twisted body, how does it have another chance? Of course we can't know. Christians have faith, but I don't think you need even be a Christian to have *hope*.

**HEBE WELBOURNE,**  
Senior Departmental Medical Officer,  
Frenchay Hospital,  
Bristol.

## Genuinely — A play for today

I CALLED in at ASBAH's main office in May to pick up a few copies of LINK and buy a book on spina bifida as part of the research I was doing for a children's play about a family with a handicapped child.

The play now shows some of the difficulties (social, economic and medical) encountered by families with handicapped children and aims to show "normal" children that we all might be handicapped at some time in our lives: and that these problems concern all of us.

I introduce an elderly gentleman in a wheelchair, and also have one of the children in the play run over by a car and reduced (temporarily) to a wheelchair. As regards spina bifida, the play does not duck the subject of the "bag" — the adult spina bifida people I talked to were unanimous that I should include it — and also talks about the valve.

When I decided to write this play I was completely ignorant of the special problems of the handicapped, and in some respects the play is an attempt to enlighten all children about the subject and combat the

prejudice and misconceptions which come from ignorance. Today's children are tomorrow's adults. I can only hope that my play will make a contribution to bringing about a radical change in social attitudes to the handicapped, thereby enabling all handicapped people to participate fully in the life of the community.

I have received much help from hospital workers, social workers, school-teachers, parents, and most of all from the many handicapped children, and their brothers and sisters whom I met whilst researching the play. In particular I should like to thank all those members of South London ASBAH who kindly gave their time to talk to me.

Perhaps local ASBAH groups could put pressure on their reps and Theatre-in-Education teams to present the play.

ROY KIFT  
Berlin

ED. NOTE: The play was to be performed in Berlin this year. When it is published in this country we will review it in LINK.

## Housing adaptations: tell us about delays

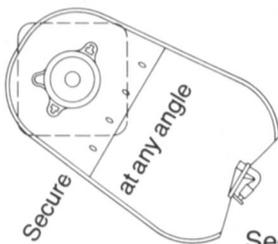
ASBAH fears that one field where families will suffer as a result of local authorities cutting back on expenditure is in the adaptation of properties. It may be that families will experience additional delays. Because of the necessity to monitor the behaviour of local authorities, ASBAH will be glad if information is passed to it regarding any delays or financial restrictions.

# New for Urostomy!

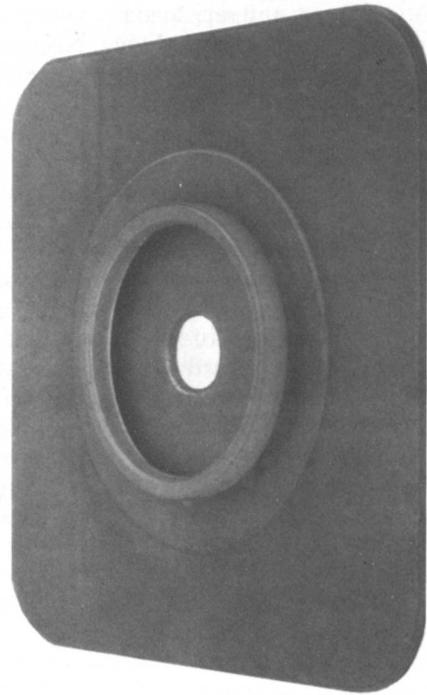
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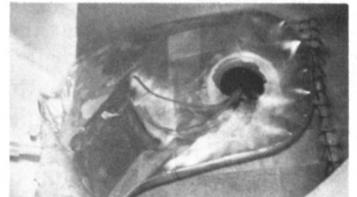
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## *The Handwriting of Spina Bifida Children*

by Joan Cambridge and Elizabeth M Anderson.

Price £1 plus 17p post and packing from ASBAH.

THERE IS now research evidence to show that many children with spina bifida and hydrocephalus have special difficulties in co-ordinating eyes and hands, and in carrying out activities using the hands — such as doing up buttons, threading, modelling, drawing . . . and more importantly in handwriting. Poor and slow handwriting can obviously impede the children's rate of learning and general progress at school.

But there is also evidence that even given a comparatively small amount of informed and systematic individual help, many such children can show marked improvements in the quality and sometimes also in the speed of their handwriting.

As a positive step towards providing advice on this subject for teachers of spina bifida children — whether in ordinary or special schools — ASBAH has recently published a new booklet *The Handwriting of Spina Bifida Children*.

It is intended primarily for teachers and for students in colleges and departments of education but may also be of interest to other professionals and to parents.

The booklet arose from the findings of a small-scale action research project, carried out jointly by the authors, Mrs Joan Cambridge, a handwriting consultant and member of the Scientific Council, the European Society for Handwriting Psychology, and Dr Elizabeth M Anderson, a Senior Research Officer at the Thomas Coram Research Unit, University of London Institute of Education.

Guidelines are given for getting the preliminaries right including pre-writing activities, motivation and emotional aspects. There is advice on writing practice, and the right tools to use, as well as a special chapter on helping spina bifida teenagers and another on left-handedness and mixed-handedness.

The design is clear and makes



**JANET HANDLEY** — who reviews *Able to Work* on this page — in fine spirit after graduating from Warwick University with an Upper Second in Sociology. She is going on to study for post graduate Certificate of Education which she hopes will lead to a teaching career.

Photo: Coventry Evening Telegraph.

this 72-page publication good to look at and easy to digest. Credit for this goes to Liz McQuiston who was responsible for the design of *Sex and Spina Bifida*.

Altogether it is an extremely valuable addition to ASBAH's range of informative publications.

### *Able to Work* by Bernadette Fallon.

Price £2.50 (plus 50p post and packing). Spinal Injuries Association, 126 Albert St., London NW1 7NF.

MANY excellent reviews of Bernadette Fallon's book *Able to Work* have been published, but I read the book as critically as I would any written by an able bodied person and proffering advice to the disabled.

*Able to Work* is written primarily for those, newly discharged from hospital, who have sustained traumatic paraplegia. The

message embodied in its title is echoed by everyone concerned with disabled people. If we could persuade prospective employers to read Ms Fallon's book we would go some way towards making them accept disabled people, with obvious benefits to all as there is a large wastage of talent among the unemployed disabled.

The book's purpose however is not to convince employers that disabled people have abilities which can be utilised, but rather to inspire a positive self image in the disabled person. He must be convinced that he is employable before he can convince others.

The book's first, and I believe best chapter, deals with what is expected of a worker. For those already employed the advice on punctuality and appearance may seem basic, but I believe that they could be very beneficial for the disabled youth who upon leaving a special school needs all the advice he can receive about making the most of himself. It is not easy for the disabled to compete for jobs against the able bodied.

The following chapters cover every aspect of work, both open and sheltered, ranging from transport to training with great sensitivity and understanding. The book does not attempt to give "the right answer" to each of the many problems facing the disabled worker, rather it lists the many possible solutions.

The book's greatest strength lies in this attempt to make people decide what is right for them as individuals rather than describing what "the disabled" do. The decision making process is helped further by the inclusion of many addresses of organisations which the reader can contact for more help.

Janet Handley

### Literary prize

CONGRATULATIONS to 17-year-old Kim Woolfe of Hoo, near Rochester, Kent who won second prize in this year's Spastics Society's Literary Contest. Kim has spina bifida and her essay 'The Forgotten Land' won her a £10 prize in the Adolescents' section of the contest.

ASBAH expanded its work to include Social Rehabilitation Courses in 1977. As is so often the case the need for this expansion was identified by parents. Early in the summer of 1977 the Sussex Association organised a holiday/training week to observe how children managed away from their usual surroundings, and to try to help them achieve more personal independence, particularly in the management of their urinary appliances and calipers. Staff from national ASBAH attended this week and its value was immediately apparent.

Additionally, ASBAH was receiving requests for help from young people themselves who found that, when they left school, they were inadequately prepared for life in the community. It was, therefore, decided to hold a pilot course organised entirely by national staff and this took place at Five Oaks at the end of 1977.

Subsequently, it was thought that this area of ASBAH's activities must be expanded as a matter of urgency and the National Executive Committee approved that a full-time national officer with special responsibility for young ASBAH (as it was originally called) should be appointed and be funded from the Association's development fund. In the meantime, more training weeks were planned. This expansion of ASBAH's activities was discussed with the Department of Health & Social Security and it was a great encouragement to the Association that a grant was made to help initiate the scheme.

To date, (June 1979), ASBAH has held six training weeks and acted as consultant for a week organised by the Frenchay Hospital. An Occupational Therapist from Queen Mary's Hospital, Carshalton, came to help at a course at Five Oaks before the first course was held at Queen Mary's.

### Sample

Fifty three students have now attended our Social Rehabilitation Courses and although this is a small sample, we have learned enough to confirm our thinking that the scheme must expand. The age range has been nine years to 32

## Lessons in d

LINK, from time to time, has carried information on the work done by ASBAH in the field of social independence training for young people with spina bifida and hydrocephalus.

Now for the first time LINK carries a full article assessing the problems so far encountered on the courses — physical, vocational and emotional problems — as well as proposals for further development in this important area of work.

The article is largely drawn from the paper prepared by ASBAH's Chief Executive Officer, *Moyna Gilbertson*, and three officers of the Association — *Barbara Newman* (Education, Training and Employment), *Jan Tomlinson* (Young ASBAH), and *Jill Vernon* (Aids and Appliances) and presented by Miss Gilbertson to the meeting of the Society for Research into Hydrocephalus and Spina Bifida in Newcastle recently.

years. Forty three had spina bifida and hydrocephalus, eight spina bifida only and two hydrocephalus. Of the students with hydrocephalus, all but three had a shunt.

### School-leavers

Following the intensive treatment of babies in the early sixties, 1976 saw a larger group of school leavers with spina bifida or hydrocephalus than had ever been met before. Their needs were so acute that our first courses were organised for the over 16 age group and it was subsequently that the age range was extended downward. Thirty girls and 23 boys have now attended. It is interesting to note that at first more girls than boys were referred and many students needed some encouragement and reassurance to come away from home. Now the bias has disappeared, the last course accommodated the same number of boys and girls and for future courses there is a waiting list from both sexes.

We discovered that there was often an unrealistic attitude on the part of schools as to the level of independence already achieved, and initially most referrals were from families. Local education and social service departments, once we had accepted students, usually

sponsored them financially. Local Associations have also helped financially and only a few families have borne the cost themselves.

By far the most usual reason for applying for a course was the problem of incontinence or bowel management. Of the 53 children and young people attending, 31 had urinary diversions, of those two had double diversions, and one also had a colostomy; 11 had penile appliances, six used manual expression, and two young people with hydrocephalus were continent.

When we consider bowel management, more than a third were continent but many were accident prone and they, therefore, felt insecure; 13 used suppositories, 10 manual evacuation — neither of these groups had had any training in self-management — three used drugs, three enemas and one had a colostomy.

### Social bar

Problems of incontinence and bowel management are undoubtedly the greatest social bar to young people being accepted, as is their right, into the community of their peers and so each course was largely devoted to this aspect of independence.

Much of the help to run these courses was provided by volunteers. However, some professionals took part, either being seconded by their employing

# do-it-yourself



g dressed

Photo: Jan Tomlinson

authority or giving up part of their holiday. ASBAH is indebted to the therapists who helped, and particularly to the staff of the Children's Division of Downs Surgical Ltd. who gave advice on the management of incontinence. Some adults with spina bifida and hydrocephalus also played their part by counselling.

## Independence Training Programme

Each course lasts for one week. To ensure continuity, each student is matched with a helper. The helper takes part in all aspects of the course, literally giving a 24-hour a day commitment. Most of each morning is devoted to helping students develop their own personal care routines. Students are taught how to change appliances and empty them regularly; to cope with bowel management problems; to be responsible for their own prescriptions for supplies, and to learn to avoid, and to check for, pressure sores.

A therapist assists with teaching other basic daily living skills — transfer to bath, lavatory, car etc. — and gives advice on problems such as dressing, climbing steps and wheelchair manoeuvres and maintenance.

The rest of the day is given over to more general aspects of independence — learning about

nutrition, planning menus, budgeting and shopping, and cooking meals. It is important to learn to cope with the restrictions of a kitchen not specifically designed for wheelchair users. Students are responsible for their own laundry and they learn to use washing machines and driers.

The effect of hydrocephalus on the ability to master daily living skills has only recently become apparent. Many young people with hydrocephalus have weak hands and poor co-ordination which cause difficulties with routine tasks such as doing up buttons, buckles on calipers, laces on shoes, using knives, scissors or can openers.

Hydrocephalus also appears to effect perception, causing problems ranging from the ability to position urinary appliances accurately, orientation in new environments and manoeuvring a wheelchair, especially in restricted spaces.

## Repetition

Poor concentration affects all tasks. Constant repetition is needed in order to learn new skills. These young people seem resistant to change, and easily confused if the same skill is taught in different ways by different people. It has often been stated that young people with spina bifida and hydrocephalus are passive and lack motivation. We have found that

they cannot exercise judgement and find it difficult to make decisions. They usually do not see any connection between their own actions and subsequent events.

We know of no evidence to show whether this is due directly to the effects of hydrocephalus; we do know that lack of mobility limits opportunities for experience, and performance may, in some cases, be affected by an inappropriate drug regime. This group is also noticeably immature, and an over-protective attitude of parents or care staff will contribute to this immaturity. The overall aim of the course is to develop all aspects of independence, and so time is spent on talks and discussion groups.

We are concerned that young people themselves have very little understanding of their own disability, and therefore try to ensure that the medical aspects of spina bifida and hydrocephalus are appropriately explained.

Personal relationships both with parents and peers are discussed, and also psychological aspects of disability.

## Experience

Course members organise their own social activities in the evenings, arranging outings to a cinema, or having a meal at a restaurant. For some it is a new experience not to be accompanied and supervised by adults.

In reviewing the course at the end of the week, the students have usually expressed their hope to take more responsibility at home and to convince their parents of their abilities. Parents who have attended the last day of the training courses have been equally enthusiastic.

A week is a very short period but it is significant that every student learned some new skills and went away professing determination to practice these. As well as routine follow-up to their homes, contact has been made as appropriate with schools, careers officers, social workers and training establishments. The students themselves have maintained a close link with the national ASBAH staff and know that they can be contacted if any problems arise.

*Continued over page*

Continued from P10

## Lessons in do-it-yourself

### THE FUTURE

Further development of this work is planned, and it is hoped to arrange courses for younger children. Undoubtedly many young people still do not know of the services of ASBAH and we trust that through our Field staff contact will be made.

We must:—

- Educate young people more efficiently as to what spina bifida and hydrocephalus are.
- Initiate more schemes to train volunteers.
- Influence professionals, for example, teachers and nurses.

Perhaps most importantly we must try to convince medical practitioners, particularly urologists, that successful surgery is not necessarily the end of the problems of incontinence and to enlist their increasing support for improvement in services.

We intend to produce a handbook for young people explaining the general problems of the disability and also a pamphlet for employers to demonstrate that it is possible to include disabled people within an ordinary work force.

We believe that it is impossible to disassociate employment or occupation from accommodation and it is, therefore, unrealistic to

concentrate on social independence training without endeavouring to make provision for suitable accommodation along with occupation or employment. It is, therefore, anticipated that we will be increasingly involved with other agencies in trying to improve facilities.

### Essential

It must be emphasised that one of the essential roles of a voluntary organisation is pointing the way to improvement of services and of co-operating with statutory provision. In the field of social rehabilitation we are much encouraged by the attitude of the Department of Health & Social Security and the Department of Education & Science who have suggested that we organise training courses for professionals and have also expressed interest in seeing reports of our findings which we hope will help in planning future expansion of services.

Additionally, the Stoma Care Nursing forum of the Royal College of Nurses and the St Bartholomews Hospital Stoma Care courses have asked us to take part in future training programmes.

For the past 10 years the Government has actively encouraged the development of Younger Disabled Units to cater

for the needs of those needing long term hospital care or a period of multi-disciplinary assessment or rehabilitation in a hospital setting, and there are now some 64 units in England which could accommodate more than a thousand residents. Whilst recognising the need for these units and applauding the initiative which established them, we are concerned that any young person able enough to live within the community should not find himself in a residential establishment for the disabled because of lack of training, counselling and guidance. This is one of the reasons why we shall be concentrating on problems of accommodation in the immediate future.

Young people now reaching school leaving age have, in our view, additional handicaps superimposed on their disability because of the lack of training in the years as they approached adolescence. We are trying to remedy this but most importantly, we must learn from the lessons they have taught us and ensure that children still at school are adequately prepared for an independent life. We hope that ASBAH will continue to take an active and imaginative part in the planning for the future for our younger disabled members.

## OBITUARY

### Elizabeth Anderson

THE SUDDEN and tragic death on Friday, August 3, 1979 of Dr Elizabeth Anderson is a loss to all of us. She had been associated with ASBAH since its early days and many families came to know her, particularly when she was working with Bernie Spain.

Her sensitive and sympathetic approach to the problems created by spina bifida and hydrocephalus and especially to those of young people approaching adult life were appreciated by all who knew her.

She became a member of Executive in 1971 and in 1973 she joined the Education, Training and

Employment Committee, the richer for her wise counsel.

She contributed to various ASBAH publications and her latest book, *The Handwriting of Spina Bifida Children*, which was prepared in collaboration with Joan Cambridge, is reviewed in this issue.

Elizabeth, who had a superb gift of communication, nevertheless remained a very private person. ASBAH has lost a great friend and we miss her.

Moyna Gilbertson

## Wayne needs a home

WAYNE is a four-year-old West Indian boy who has hydrocephalus and is in the care of the City of Birmingham in a nursery. He needs a long-term foster or adoptive home. If anyone would like to know more, please contact Joan Collins, Centre 2, Social Services Dept, 23 All Saints Rd., Hockley, Birmingham 18. Tel: 021 523 4361.

# Growing Concern?

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## THE RELIABLE SOURCE OF SUPPLY

# WHEEL

A **DISABLED** person with limited walking ability, and whose need for a wheelchair is permanent, may be supplied with one by the Department of Health and Social Security. It is issued on the recommendation of any National Health Service doctor, via the patient's local Artificial Limb and Appliance Centre.

In practice, DHSS can provide a wide selection of vehicles, in addition to standard wheelchairs, ranging from trolleys and pushchairs for younger children, to bicycles, tricycles and lever chairs for older children and adults.

Many of those with spina bifida have special needs, and it is best if a therapist can provide the initial assessment, with the final recommendation being made by a hospital consultant, to make sure that the vehicle chosen is medically suitable, and also that it will fit into the home environment.

This article is written to bring you up to date with some of the vehicles currently available which are particularly suitable for those with spina bifida. However, some of these vehicles are 'special' ones, outside the standard DHSS range, and so are more expensive, will take longer to arrive, and your consultant will have to make a strong medical case to justify their issue.



**HAND** propelled trolleys such as the Shasbah Trolley (above) and the Chailey Chariot, mean that very young children can start to explore the world as soon as they can sit. The Shasbah Trolley is also available in a larger size.



**THE BABY** Buggy pushchair is issued for the youngest children, and an alternative, the Cindico Traveller (above), which provides rather better support, may also be provided.



**THE TRI-AID** hand propelled tricycles are suitable for more severely disabled children. The tricycle is available in 2 sizes and can be fitted with either a footplate, or leg-rests for children wearing calipers.

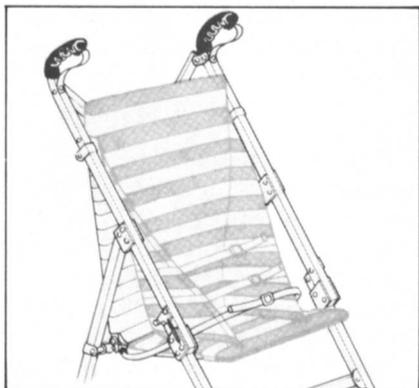


A **LEVER** propelled tricycle, Model 33C, can be issued for young children weighing up to six stone.

**SEVERAL** modifications and accessories are available for the standard range of DHSS wheelchairs, and you may not be aware of all of these. For example, the child's chair Model 8LC is now available with coloured paintwork and upholstery, in orange/green and silver/red colour schemes, and

this chair can also be issued with a rigid seat and backrest to give more support. Most chairs are available with a folding backrest, which makes them easier to store and transport. Accessories such as detachable trays, crutch holders, and a zipped backrest canvas may also be available.

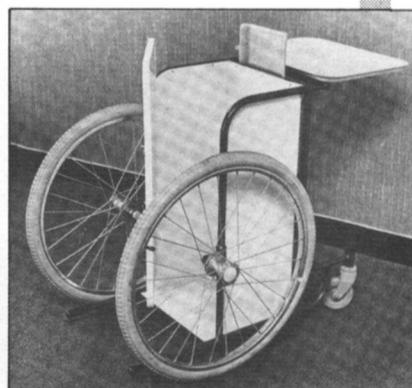
# POWER



**THE MAJOR Buggy** is a pushchair for older children, and it can be fitted with an Intermediate Seat, giving better support, and catering for the 'in-between' sizes.



**THE EXPLORER** is a new and very versatile vehicle, which can either be self-propelled or used as a pushchair. It was designed particularly for children in plaster following surgery, or for those who have to lie prone. The seat base and backrest can be adjusted to a wide range of positions, and an adjustable headrest is available.

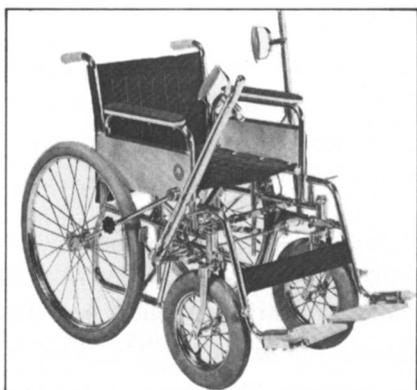


**THE YORKHILL Chariot** is a "standing box on wheels", for children who need support to stand, but also need to be mobile in the upright position. It is available in three standard sizes or may also be made to measure.



**THE DHSS** range now also includes foot propelled Raleigh two-wheeler bicycles, fitted with outriggers and also the Hayes Jaybike (above). However, these bicycles are only likely to be suitable for children with fairly good use of hip and leg muscles.

**MANY CHILDREN** and young people with spina bifida are susceptible to the dangers of pressure sores, particularly as they get older and heavier, and may be spending longer periods sitting in a chair, and there are several accessories to help



**THE MEYRA-REHAB** Lever chairs are now available for the oldest children and adults, and can provide faster, more efficient mobility outdoors than the standard wheelchair.

prevent pressure sore problems. Chairs can be fitted with upholstered cushions, and sheepskins. Spenco Emulsion Cushions, and Powered Ripple cushions may be issued to those at great risk.

**IF YOU** wish to purchase any of these vehicles privately, further information is available from the following manufacturers:—

**SHASBAH TROLLEY**  
Mrs Charrett, 46 Tilbrook Road,  
Regents Park, SOUTHAMPTON.

**BABY BUGGY, MAJOR BUGGY**  
Andrews Maclaren Ltd., Station  
Works, Long Buckby,  
NORTHAMPTON.

**CINDICO TRAVELLER**  
Cindico Ltd., Skerne Road, Driffield,  
NORTH HUMBERSIDE.

**EXPLORER**  
Lawrence Wilson & Son Ltd., Silver  
Cross, Guisley, LEEDS.

**TRI-AID TRICYCLES**  
Tri-Aid Ltd., 29 James Watt Place,  
College Milton North, East Kilbride,  
LANARKSHIRE.

**JAY BIKE**  
R C Hayes, 65a Main Street, Kirby  
Muxloe, LEICESTER.

**YORKHILL CHARIOT**  
Robert Kellie & Son Ltd., Rutherford  
Road, Dryburgh Industrial Estate,  
DUNDEE.

**LEVER CHAIR**  
Meyra-Rehab (UK) Ltd., Unit 4,  
Copheap Lane, Warminster, WILTS.

# RING IN THE CHANGES

**TO ENABLE individual societies and regions to purchase cash collection and flagday material at favourable rates — at a discount in effect — we have arranged with Angal Limited, for several years now, to make available a Collector's Kit and Replacements to an agreed ASBAH 'uniform'.**

The COLLECTOR'S KIT SCHEME is fast and convenient, saving you, and us, the expense in time and labour of much of the administrative work involved, and we shall continue to take advantage of the service. But, we have made changes to that 'uniform'.

As you no doubt know, ASBAH received quite a number of complaints concerning our previous collection media and its statement 'He is Spina Bifida — Please Help'. I am in total agreement that this was not altogether an acceptable approach and, I feel, that the bell symbol has many advantages over the old format.

Apart from the collecting material shown in the photographs we are also discussing with Angal the production of bar collection media which may take the form of a large collecting vessel with a small bell suspended inside, which will ring when a coin is inserted.

I should welcome any comments in connection with this as I am sure that it would be a very painless and effective way of raising funds within local associations and obviously the more items of this type the cheaper they would become.

National ASBAH also ran an appeal to businesses last year, whereby we asked companies to sponsor "changes" (there are 5,000 of such) in a special peal of bells which was rung out from a London



church. A charge of £10 was made to sponsor a change and the 'appeal' brought in approximately £1,100 net.

You might like to think about approaching church bell ringers in your own area to do something similar. It would be nice to have a day when church bells throughout the country rang out in support of ASBAH, both local and national, and again I would welcome your thoughts and comments.

From the photograph (on the facing page) you will see the white satin sash on which is printed 'Support Your Local Group' and for which we have not quoted a price. If you wish to order any sashes please order them direct

from us at Tavistock Square as, in a rare flash of generosity, I am offering these FREE to local associations while stocks last! When this stock does run out we have a new sash which also carries the bell motif in line with the rest of the media, but these will cost £1.00 each.

The new material is available from stock now for delivery within two weeks of an order. Just write or telephone your order to:—

Angal Limited, 48a Holmbush Road, Putney, London SW15 3LE  
Tel: 01-788 5464.

They will invoice you direct. Full details of the new Kit and Replacements are illustrated on this page.

## FULL FLAGDAY KIT

1 Polybox Handbox (green), fully labelled with two 4" × 3" Main Labels and Reseal Ring label, incorporating an Authorise Collector's Badge/Box Identity Sticker, plus 4 spare Reseal Rings.

1 Wallet (green/white), containing 252 Flagday Emblems in sheets of 18. String supplied, not fitted. . . . . **£1.35 complete**

## PART KIT

As above, less Wallet and Emblems. . . . . **60p each**

## REPLACEMENTS

Reseal Ring, incorporating Authorised Collector's Badge/Box Identity Sticker. . . . . **£1 per 100 or £8.50 per 1,000**

Main Label 4" × 3" self-adhesive PVC (2 per box). . . . . **8p each**

Wallet with string supplied, not fitted. . . . . **24p each**

Flagday Emblem 1" × 1½" rect. in sheets of 18. . . . . **£1.20 per 1,000**

Standard handling charge per consignment valued at under £10 (not charged for items sent by post at Min. letter rate). . . . . **£1.25**

Carriage & VAT are extra to the above and will be added to invoice.

**Kits and replacements are available from stock. The kit and part kit are supplied fully labelled ready for use.**

Collectors' envelopes, flat folding cardboard boxes for posting, labels, button badges, sashes and other cash collecting items are available from Angal on request; though not necessarily obtainable ex-stock.

THE GREEN Polybox Handbox, specially designed for hand-held collections, has a white funnel slot to encourage higher individual donations and to make the collector's job easier especially at busy locations. Multiple coins as well as notes, may be dropped into the box with great ease and there is no excuse for donors to hesitate.

A reseal ring label, printed green on white, bearing the ASBAH message and logo, provides a positive seal at the top of the box, and comes with a 1 11/16" diameter authorised collector's badge box identity sticker giving box no/date/name of collector and the society's title, leaving space for an address.

The main label, two per box printed green on 4" × 3" gloss white self-adhesive PVC, is virtually permanent and need not be disturbed when the box is opened and resealed.



— **Come and buy** —  
**ASBAH offers new items for sale**

**I AM SURE** that we are all finding raising funds increasingly difficult with inflation running as it is but **I hope** that the information on the previous page will be of some assistance to everybody in meeting their targets during the coming months.

In addition to the new collection material we are also trying to extend our range of saleable items and are now in a position to offer, in addition to green and white pens, gold pens and key rings; a very attractive First Aid Kit at £3.25, retailing at £4.00; a Wash Kit, which is a must for any members who may be going away to stay in chalets or caravans, at £2.75, retailing at £3.50; a Crisis Kit at 85p, retailing at £1.00; a Carry Game bearing the ASBAH logo, which is a heavy duty plastic pouch with a chess board printed on one side and another game called Nine Mens Morris on the reverse. The bag contains counters for both these games and will also double up as a useful beach bag. The cost of this to Local Associations is £1.50, retailing at £2.00.

Other items, including a small telephone index, a home tool kit, a calling card file, a pocket sewing kit and a digital thermometer, are on order and details of prices will be available soon. We are also considering linen tea towels and T-shirts and any indication of your potential interest in these would help us in arriving at a decision.

I very much hope that these additional items and services will be of assistance to you in your fund raising as I know that we all wish to make this a ring-a-ding year for ASBAH!!!

JUDY KAY

**THE Newton YORKHILL**



**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.

For further details contact:

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in addition to the finest ostomy equipment, a service throughout the country which is designed to care for ostomists.

Qualified stoma fitters and ostomy appliance advisors are available to help with any problem associated with the wearing of appliances. These services are free from charge, and are without obligation.

Troubles with leakage, odour, soreness around the

stoma, skin excoriation, and allergy, are effectively dealt with every day.

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", 1¼" and 1½".

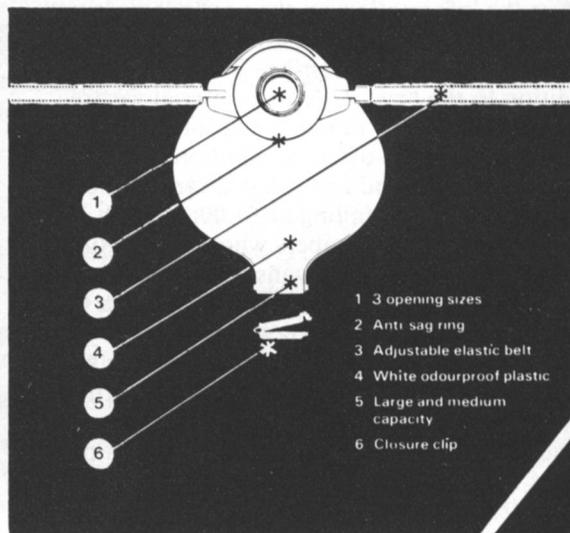
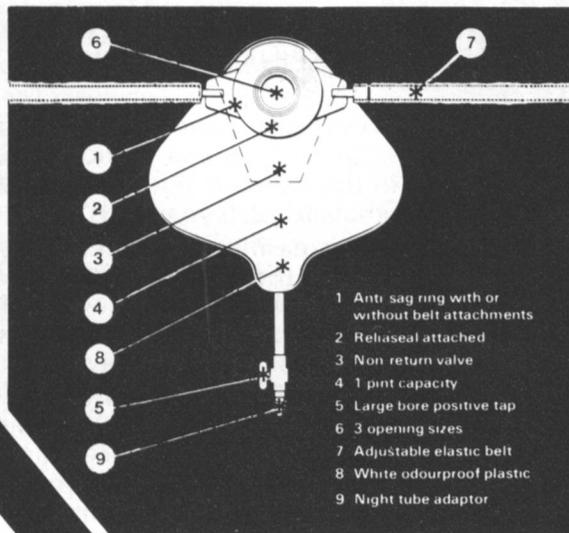
### LIGHT WHITE ILEOSTOMY POUCHES

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", 1¼" and 1½".



If you would like to try either of the above appliances, please complete the coupon opposite and post to the address below. **NO STAMP IS REQUIRED**. You will then receive a sample of the basic appliance free from charge and without obligation.

**IMPORTANT**

To obtain the best result, please state the diameter of your stoma. If you cannot measure accurately please ask Salts for a stoma measurement guide.

**SALT & SON LIMITED,  
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L/78/0/1

NAME .....

ADDRESS .....

TYPE OF APPLIANCE ..... OPENING.....

## CLASSIFIED 'ADS'

Unfortunately due to increased printing charges for LINK we are having to slightly raise the advertising rate. As from the Jan/Feb issue the classified advertising rate will be:

£1.50 for up to 30 words. £2.50 for 30-45 words. £3.50 for 45-65 words. Please send remittance with your advert. You may like to pay for a whole year's advertising in one go.

Adverts for the next LINK — the Nov/Dec issue — should be in by October 5 at the latest.

### HOLIDAY ACCOMMODATION

**CAMBER SANDS:** Well-equipped and adapted chalet (sleeps 6). Bookings taken from January by Mrs J. Wilson, 23 Sunnysdale 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.

**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.

### 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.



### THE SHASBAH TROLLEY FOR HANDICAPPED CHILDREN

Patent applied for in UK, Commonwealth Countries, USA, Canada

**Standard model** for children 1-5 years: £20 plus carriage.

**Large model** for children 5-10 years: £25 plus carriage:

Overseas prices on application

Produced by **Southampton and District ASBAH**

All enquiries to: Mrs K. Charrett, 46 Tillbrook Road, Regents Park, Southampton.

## ASBAH booklets etc . . .

<i>Your Child with Spina Bifida,</i> by J. Lorber, MD, FRCP	25p
<i>Your Child with Hydrocephalus,</i> by J. Lorber, MD, FRCP	20p
<i>Children with Spina Bifida at School,</i> Ed. P. Henderson, CB, MD, DPH	30p
<i>The Care of an Ileal Conduit and Urinary Appliances,</i> by E. Durham Smith, MD, MS, FRACS, FACS, and others	15p
<i>Aids and Equipment</i>	*60p
<i>Sex and Spina Bifida</i> by Bill Stewart	*£1

(75p to LIFT members)

*The Handwriting of Spina Bifida Children*  
by Joan Cambridge and Elizabeth M Anderson ... \*£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 12p per booklet.  
\* Postage - 17p.

### Scottish Spina Bifida Association Booklets

<i>Growing up with Spina Bifida</i>	30p
<i>The Spina Bifida Baby</i>	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

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

All available from Appeals Dept.—postage extra.

**The Appeals Dept.** carries a range of fund-raising items, i.e. pens, key rings, kits, games, etc.

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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