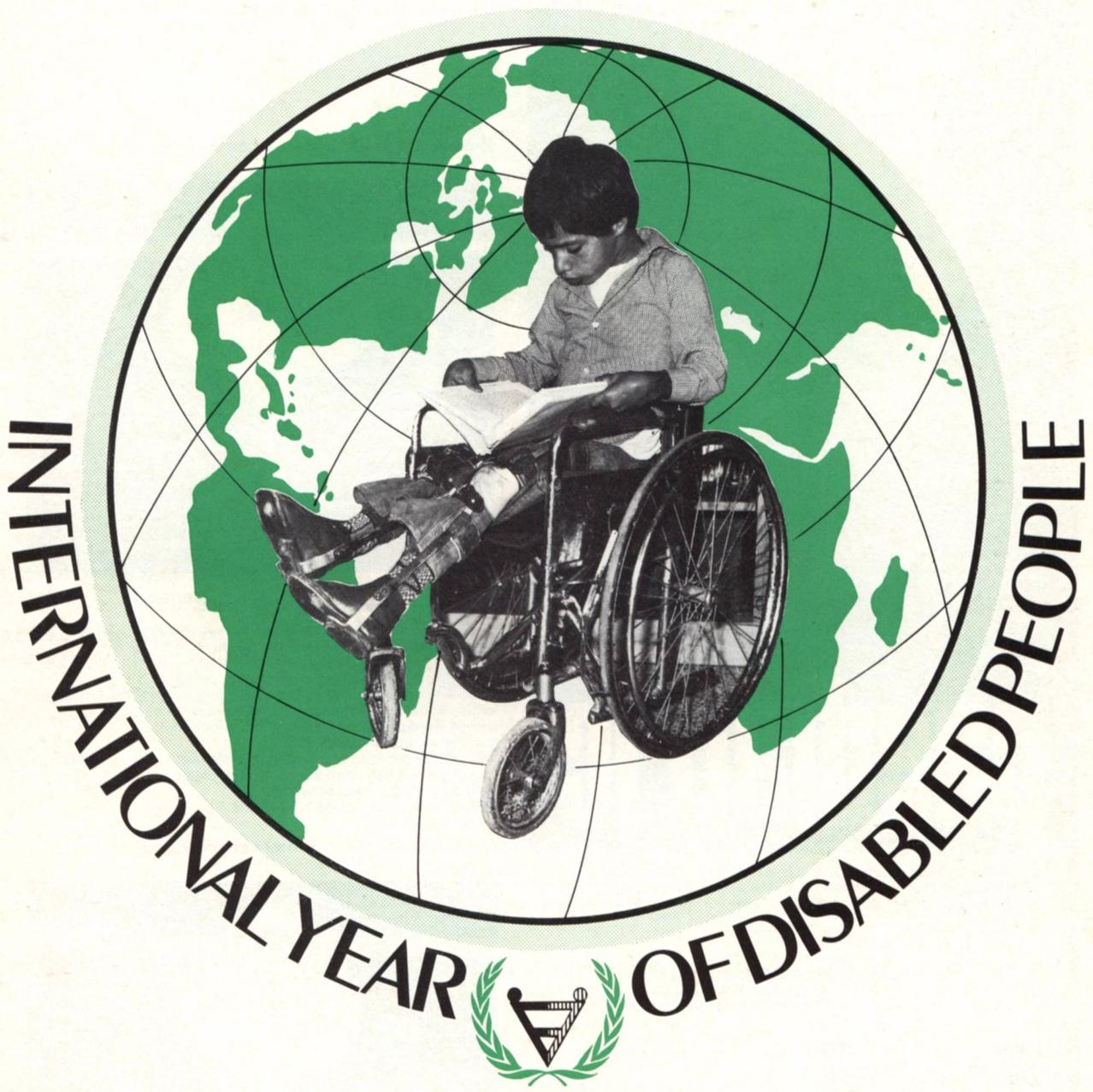


Link



Association for Spina Bifida and Hydrocephalus/ASBAH 15p

Jan/Feb 81



The job of publicity agent: One hundred firms set example:
IYDP—a visit to Israel: Newcastle clinic helps young adults:
Antenatal diagnosis: Naidex: An appeals recipe



Stoma products
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The external dimensions of the pouches are:-
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(6³/₄" x 4") approx.
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paediatric

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Further details of these exciting new appliances can be obtained by returning the coupon below to Salts. If you are particularly interested in any particular application please tick the appropriate box provided on the coupon.

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(L/P/81)

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

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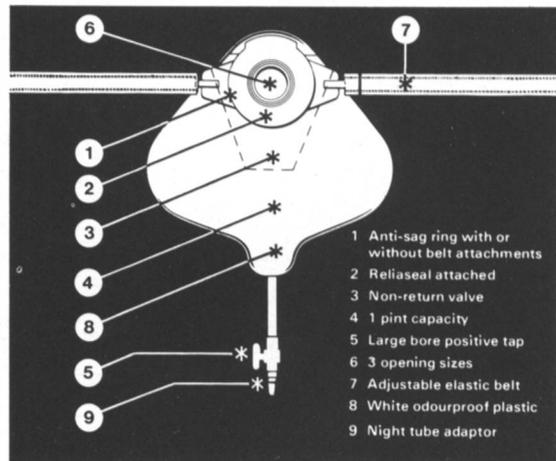
are complete appliances and can be worn without any additional accessories, though some ostomists prefer the added feeling of security which LW accessories can provide.

LW is disposable, is odourproof, is soft and rustle free, is self-adhesive, and can be worn for up to one week before changing.

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3 opening sizes available: 1", 1¹/₄" and 1¹/₂".

* Now available in Small capacity size



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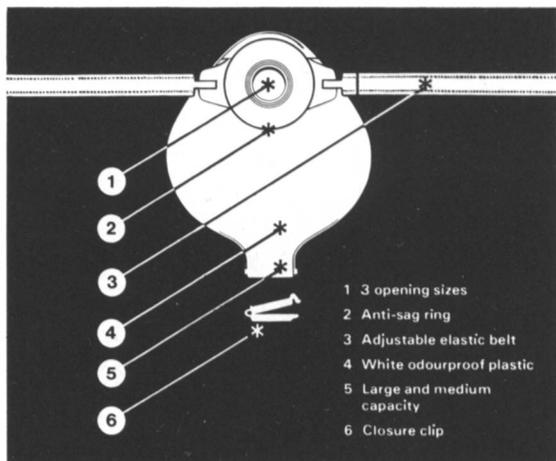
can be worn without any additional accessories, though some ostomists prefer the added feeling of security which LW accessories can provide.

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Any ostomy adhesive and sealing washers are suitable. None can harm the tough, soft plastic. Reliaseal is highly recommended.

3 opening sizes available: 1", 1¹/₄" and 1¹/₂".

* Now available in Small capacity size



Link ⁷²

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

Patron:

HRH The Duchess of Gloucester

Chairman: Mr O J Colman

Hon Treasurer: Mr R M Nichols

ASBAH has an experienced staff
ready to help with any problems
relating to those with spina bifida
and hydrocephalus.

Chief Executive Officer:

Miss M P Gilbertson, MCSP

Finance Officer:

Mr F G Armour, FCA

Director of Appeals:

Miss Judy Kay, MIPR

Head of Field Work:

Mr H Croydon

Education, Training & Employment

Officer: Mrs B Newman

Disabled Living Adviser:

Miss J Vernon, BSc

Information Officer:

Miss B Holland

LINK Editor:

Mrs S I Gearing

IT'S HERE—1981 International Year of Disabled People. And at the outset it is as well to remind ourselves just what it is all about.

Quite simply, but quite ambitiously, in 1981 we hope that people in this country, and around the world, will set about changing general attitudes towards the disabled. For it is in these general attitudes that the key to improved access, employment, mobility and personal opportunities for disabled people is to be found.

The disabled have real needs but they also have real abilities and qualities to offer society at large. In a balanced presentation of the case, we hope that at least some of the more negative attitudes which have prevailed for centuries can be changed once and for all.

Internationally, the UN is arranging technical exchanges and other opportunities for people to share their expertise in prevention and rehabilitation. Preventing disability, particularly in the third world, is a major priority for IYDP. The public must be adequately informed about preventative measures available at present; improved provision and legislation must be sought in 1981. International co-operation is not just a matter for the UN: national and local societies can arrange exchanges with their opposite numbers abroad, and local authorities can make disability the theme of 1981 'Twin Town' visits.

The National Council for Voluntary Organisations has set up a Committee to stimulate and co-ordinate work in England for IYDP, at the request of the Department of Health & Social Security which is co-ordinating the Government's contribution to the Year. A majority of the committee members are either disabled or the parents of handicapped children.

The IYDP organisation is distributing information and material for the Year nationally, particularly to the media. Someone with a disability taking part in a programme without their disability being relevant can lead to greater public acceptance of disability—'Ironsides' & 'Crossroads' have probably done more for integration than separate specialist programmes just for disabled people.

Members of Parliament (in both Europe and the UK) are being asked to take part in the Year with Parliamentary initiatives and support for constituency projects. Political parties have also been asked to participate as have nationalised industries, pubs, churches and banks to name just a few. The CBI and TUC have been asked to improve employment opportunities for disabled people. Projects which give more understanding of the problems of disability are being made available to schools.

Throughout England, Local Associations of Disabled and Councils of Voluntary Service are working with local groups of national societies, churches, women's and youth organisations, Community Health Councils, local authorities, trades councils, chambers of commerce, fund-raising and other community groups to put on local events and campaigns for IYDP. They will welcome your support and involvement.

What kind of events? Whatever local disabled people want. But the IYDP Committee stresses that events must be of lasting value if the Year is to be a success. 'Lasting' means not just tangible improvements like ramps and induction systems, although more would be welcome. It also means campaigns which lead to greater understanding and realisation that it is the individual, not the disability, which counts. Indeed, the real disabilities are physical obstacles and society's attitudinal barriers.

Changing attitudes sounds like a rather grand and formal endeavour. But it can also be fun. So enjoy yourselves, help others to enjoy themselves, but above all make 'em think.

STAFF AT ASBAH—and no doubt many LINK readers—were delighted by a feature in the *Observer* on Sunday November 16.

The Business page carried a feature on commercial winemaker Alan McKechnie and his vineyard in Gloucestershire. A picture showed Mr McKechnie sampling a glass of wine, and it also showed that he was in a wheelchair. What was heartening was that the report didn't mention that he was disabled. The newspaper obviously considered that his disability wasn't relevant... and neither was it.

Let us hope that more papers will carry reports about the achievements of individual people without feeling it necessary to label them as disabled.

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FRONT COVER: Just one of the world's disabled people whose needs will be highlighted during 1981. This young student lives in Israel and on the centre pages of this issue Link takes a look at the Alyn centre in that country.

The yearly subscription for LINK (UK) is £1.85, which includes postage. While every care is taken to ensure accuracy of information published in LINK the publishers can accept no liability. Opinions expressed in articles are not necessarily those of ASBAH.

Sara shows she means business

PRIZE-WINNING students (pictured right) of Ludlow College in Shropshire, and among them is Sara Carter (in the wheelchair). Her mother sent this happy photograph to LINK in the hope that it might encourage other hydrocephalic young people to continue with their studies.

She writes: 'Sara spent her school years at residential school, but she wanted to come home and join a business study college—luckily Ludlow College offered her a place.

'Despite valve troubles during the first year and an operation which caused her to miss exams, she got the Principal's prize. At the end of Speech Day, Sara said to me—'I didn't know whether I could cope with an able-bodied college course, but today proves I can''.

Photo: P. G. Bartlett



Photo: A. C. Murrey

MR RONNIE GOWAN & MISS LORRAINE WEBB

FACING the future together—Ronnie Gowan and Lorraine Webb (above) both of whom have spina bifida, pictured on their wedding day at St John's Church, Whittle-le-Woods, Chorley, Lancs.

After the reception they left in their adapted mini for a honeymoon in Wales.

Ronnie, 36 and Lorraine, 19, met three years ago at a training centre in Manchester.

Preston Council found them a flat and adapted it for them, but unfortunately, at the time of their wedding both of them were without jobs.

MR CHRISTOPHER LLOYD & MISS ANNETTE BRAYLEY

PROUD mother, Mrs A Brayley of Bitterne Park, Southampton, sent LINK this happy picture (right) of her daughter Annette on her wedding day at the end of August last year.

She writes: 'Over the past 24 years I have watched with delight the progress, be it slow, of Annette. Until last year she took the great step of going to Disney World with Mobility International. This called for a great deal of saving on Annette's part and more than a little help from members of the family and of course friends like Mr Macfarlane from ASBAH and the local Southampton group.

This proved to be a wonderful opportunity for Annette to see the USA and meet people from all over the world and see how other people cope with their disabilities.

Just before leaving for America, Annette went 'Banger Racing' with the local spina bifida group. Whilst there she got into conversation with a St John Ambulance man, Christopher Lloyd, and from there on friendship, then love ensued.

At Christmas Annette and Christopher got engaged and on August the 30th they were married and a very happy couple they made.

Raglan Court Housing Association allocated them a two-bedroom flat just in time for the great day.'



Campaign

FOLLOWING the report 'Campaign raises £30,000' in the last LINK, Mrs C. Byrne of South London Association has pointed out that it was not NASBAH which started the Campaign, but the Variety Club in November 1978... 'They gave £2,500... a Committee was formed which approached the local associations (we gave £2,000) and the public... The League of Friends of the Hospital also raised £5,000...'

It is clear that the successful campaign to buy the Image Intensifier was the result of tremendous effort by many people and different groups, including NASBAH.



Photo: Sleaford Standard

Athletes meet Olympic star

OLYMPIC pentathlon gold medallist, Danny Nightingale (above) chats with award winners in the physically handicapped section of the Sleaford District Festival of Sport in Lincolnshire. On the left is Clive Wright of Grantham local association who won the special trophy from the Lincolnshire Society for the Physically Handicapped. Other winners from Grantham Association were Linda Sidnell and Sharon Hopewell. All three are in their teens and have been greatly encouraged by their sporting success.

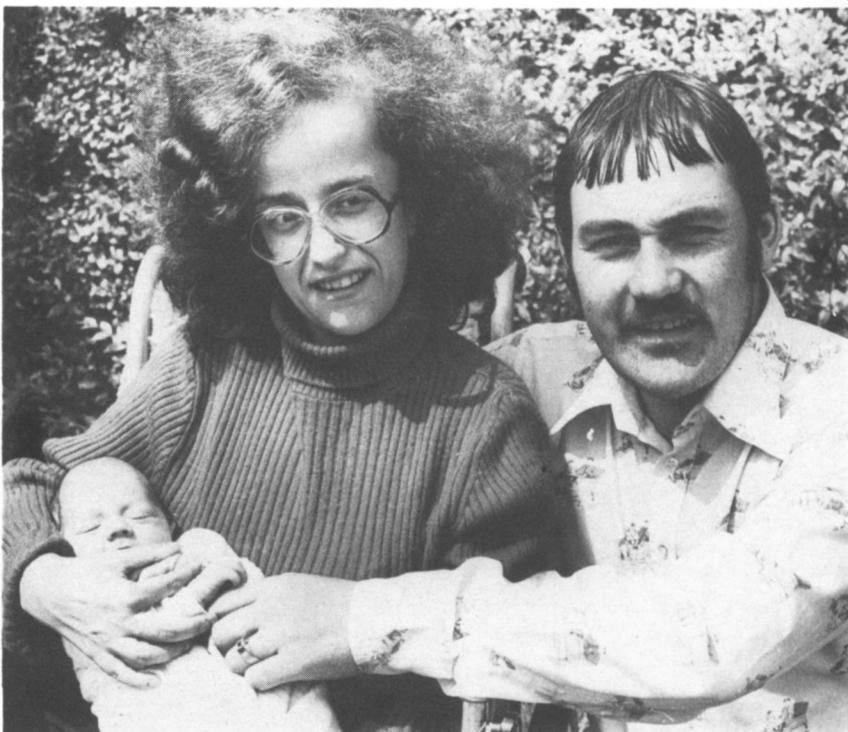


Photo: Mercury Press Agency, Liverpool

Paula—the Cooper's pride and joy

HELEN and Roger Cooper of Ellesmere Port with new arrival Paula who has brought them a lot of hard work, but mostly a lot of joy.

Helen was born with spina bifida and is in a wheelchair. She had been told that she wouldn't be able to have a baby but she never gave up hope.

She met Roger at Derwen College and they were married in the summer of 1971.

Helen had one miscarriage and

had begun to think that maybe the doctors were right and that she would never be a mother. But to her surprise she found she was pregnant again and after a normal pregnancy she gave birth to a healthy 6 lb 10 oz baby girl by caesarian section.

'Roger told me she was fine, and the next thing I can remember is hearing her for the first time. I could not believe that she was really here and I began to cry.'

Paula has changed quite a lot since the picture was taken and is now a bouncing, healthy six-month-old baby, the pride and joy of Helen and Roger's lives.



Here's to the Cross Keys

←MRS JUNE Child (centre) of the Cross Keys Inn, Melbourne near York with her customers who have been supporting the local association in Hull for many years. The photograph shows them with a youngster from the Association—Darryl—who was presented with a light-weight wheelchair bought by the Inn.

It will make it much easier for him to get around, and for his mother to push him to the local school.

The Cross Keys' customers also bought chairs for Gaynor Bowering and Betty Wardale, and helped by raising money for the Association's annual trip to Holland.

Photo: York Evening News

MY NAME is Joan Asken and I am married with three children; Mark age 11³/₄, Victoria age nine years and Juliet who has spina bifida, and is six in March. I have been a member of the Grantham Branch of the Association for about 2¹/₂ years. The Association itself was only formed three years ago and I and my family joined after moving into the area from Sunderland.

My job in the Association is Publicity Agent. It came about by accident really. There was an item of news which needed to be inserted into the local paper, which is only printed once a week. As the other members of the group had other jobs to do and I was going into town that day, I volunteered to take it. From then on I usually took the articles into the paper's offices, I work at the local hospital but only in the evenings, so I was free during the day, when the articles had to go in. If for any reason I am unable to go another member of the group will step in.

GRADUATED

From there I graduated to writing the articles, which are occasionally rewritten, but are mostly printed much as I write them, apart from minor alterations. If we have two articles in one week for the paper I usually keep one back for the following week as I think we get more publicity if we have two small articles rather than one large one. At least we have our name in the paper and that means in the public eye. This of course only applies to the results of our fund-raising efforts and not to items of real news value which must be printed in the earliest edition of the paper possible.

I also usually put up posters announcing Jumble Sales, Fayres etc (whatever we are doing to raise money) with the help of other members, in local shop windows. I also put up posters giving details of where the Association is based and phone numbers where members

How Joan Asken stepped "accidentally" into the publicity job—and how it grew from there

LINK frequently asks local associations to keep it informed of what they are doing, their plans and problems . . . One association—Grantham—has tackled this problem, and its more general need for publicity, by appointing a publicity agent from among its members. As a result LINK and everyone else is kept very well informed of Grantham news. LINK asked the Publicity Agent, Joan Asken, to write about what she does for the local group.



Joan Asken and her daughter, Juliet.

may be contacted, should members of the public wish to join us or offer us their help. These usually are displayed in public places eg Doctors' Surgeries, Health Clinics, Hospitals, the Library etc.

At the time of writing we are planning a Grand Christmas Fayre for December and have a patchwork quilt as first prize in a raffle to be drawn there. We have had the quilt on display in a local building society window with a large card giving details of the lady who made it for us and also of the Group's aims.

The quilt is also to be

displayed in an insurance company's window.

We are, at present, raising money to buy lightweight aluminium wheelchairs (individually tailored for each child) for the children who need them. Children who are not sufficiently handicapped to have need of a wheelchair may have alternative items to the same value e.g. a bicycle or an orthopaedic bed etc. As each chair costs in the region of £300 we need all the publicity we can get, but we are very lucky in that various groups of fund-raising persons sometimes choose us from the hundreds of charities they could favour, and this boosts considerably the amounts we raise ourselves.

CHALET

Since our branch of the Association was formed three years ago we have raised enough money to buy a six berth Holiday Chalet on the East Coast, convert it for use by a person in a wheelchair, redecorate and refurnish it. We have provided all the children with mock sheepskin underblankets for extra warmth at night and are now about half way down the list for our "Wheelchair Project". This is in addition to providing outings in the Summer, pantomimes in the Winter and Christmas Parties etc.

We are very lucky as we (the members of the group) get on well together the majority of the time and any differences are soon sorted out at our monthly meetings. We each have our own job and do it to the best of our ability, but if we need assistance we know the other members are there and are always willing to lend a hand should it be necessary.



INCONTINENCE? THERE'S NO NEED TO WORRY ABOUT THAT.

Downs Surgical has taken care of the problem with its full range of incontinence aids for disabled children and young people.

Downs team of trained childrens' nurses provides an expert fitting and advisory service to childrens' hospitals and special schools nationwide, as well as at clinics in Mitcham and Chiron House in London's West End. In certain cases home visits can be arranged.

Rest assured that Downs Surgical is the expert in supplying a professional service to children and young people in the field of incontinence care.



Write now for 'Able to Grow Up', Downs new free booklet to assist the professional management of the young incontinent person.

To: The Disposable Products Division,
Downs Surgical Limited,
Church Path, Mitcham,
Surrey CR4 3UE, England.

Please send me . . . copies of your
free booklet 'Able to Grow Up'.

Name _____ Title _____

Position _____

Address _____

_____ Telephone _____



DOWN'S personal products

Downs Surgical Limited, Church Path, Mitcham, Surrey CR4 3UE, England.
Telephone: 01-640 3422 or 01-648 6291.

Pension test under review

THE Department of Health and Social Services is reviewing the qualification test used for the Housewives Non Contributory Invalidity Pension, following complaints that the test is unfair and a blatant discrimination against married women.

Researcher Caroline Glendinning carried out a study of the problem for the Equal Opportunities Commission.

Men and single women qualify for the £16.30 a week pension if they can prove that their handicap stops them working, but housewives have to be tested on their ability to do household duties even if they have been forced to give up work because of their disability. They have to answer a questionnaire about whether they can still wash up, cook, shop and clean, then their doctor carries out tests to see how incapacitated they are and his assessment goes to the authorities.

Since the scheme began in 1977 more than half the 86,000 housewives who applied have been rejected, although many of them are quite severely incapacitated.

Some had been granted the benefit only after an appeal. "As well as coping with the pain, exhaustion and restrictions which serious ill-health or disablement imposed on their daily lives, they had to suffer the additional anxiety and stress of a Tribunal appeal" says Caroline Glendinning in her booklet 'After Working all these years'.*

The booklet gives a number of case histories:

Mr McG has had multiple sclerosis for five years. She cannot lift light objects, walk short distances or climb stairs. She can only do the shopping with help, and cannot do any cooking, washing up, heavy cleaning, ironing, household laundry or make the beds. Yet she too was only awarded HNCIP after a Tribunal hearing.

*'After Working all these years'. £1 by post from the Disability Alliance, 1 Cambridge Terrace, London NW1 4JL.
Tel: 01-935 4992.

London hotel—a step nearer

PLANS to build a hotel in London for the disabled went a step further at the end of the year when a bid was made for a GLC-owned site in Lambeth.

LINK reported in its last issue that John Groom's Association for the Disabled was pressing for the hotel. Five charities have joined John Groom's to form a consortium called the London Hotel for the Disabled. This group is confident of being able to raise the £1,500,000 needed to build the hotel, a single-storey building with up to 60 rooms, all of them accessible and adapted.

John Groom's Director Mr Charles Moore, said it was the first venture of its kind in London, and so far as he knew, the first in any European capital.

He said: "There are a large number of disabled people who pass through London either on their way to hospital appointments or to visit relatives or for a holiday.

By running the hotel on a non-profit making basis it is hoped that charges for bed and breakfast would be about £10.

The consortium is made up of John Groom's, RADAR, the Greater London Association for the Disabled, the Leonard Cheshire Foundation, the British Polio Fellowship and the Spinal Injuries Association.

David needs a home

DAVID who is four years old has special needs but most of all he needs a long-term foster home as he is unable to return to live with his parents.

He is just beginning to develop speech, fast developing the ability to use swivel walkers and is an engaging, active little lad who should respond within a family who are able to contend with some of the additional implications of spina bifida and hydrocephalus such as incontinence. If you could offer David a long-term home, please contact me.

HARRY CROYDON
Head of Field Work

One hundred firms set example

THE FIRST "Fit for Work" awards were made at the end of the year to the top 100 companies who were judged to be setting an example to industry and commerce in their attitude to the employment of disabled people.

There were over 400 applications from all over the country, all of a high calibre.

"If the general standard of employers in this country were to come up to the average standard of those who applied for the Award then the problems of employing disabled people would vanish overnight" said Mr Geoffrey Gilbertson, Chairman of the Judging Committee.

The Scheme was introduced as part of the recent "Fit for Work Campaign", and the idea is to give public recognition to employers who excel in carrying out constructive policies towards disabled people.

The judges found that the firms who most closely matched their guidelines were those who already employed a high proportion of disabled employees—for example, one small enterprise in Yorkshire had 33 per cent disabled workers.

Some firms gave disabled people first refusal on every vacancy arising while many of the winners ensured, with much thought and effort, that an individual disabled employee was employed in the job for which that person was most qualified.

Many employers made extensive use of Government-funded special aids and adaptations and helped with mobility both at work and in getting to and from work.

All the firms named in the awards had made a special effort in developing to the full the abilities and potential of disabled people.

It would appear that the greatest efforts towards employing disabled people are, in fact, being made in areas of high unemployment. The South of England, for instance, was very poorly represented with only six award winners, and London only managed another six.

LINK will report more fully on the award winners in the next issue.

The Award is a specially designed trophy, a plaque and a citation, and is for three years, after which employers can re-apply for a further Award.

Applications for the 1981 Award are invited covering the year to March 31, 1981. Firms wishing to apply, or organisation such as employers' associations, trade unions, voluntary bodies etc., who wish to nominate a firm, should contact local Disablement Resettlement Officer at the Jobcentre or Employment Office.

New arrangements on employment

NEW arrangements to assist the employment of disabled people have been announced following the review by the National Advisory Council on Employment of Disabled People.

The Manpower Services Commission's advisory committees will be replaced by individual members of the local community working outside committees, and by 88 new Committees for Employment of Disabled People.

Selected members of the local community will work on an individual basis with MSC's Disablement Resettlement Officers, helping them to find work for the disabled people in that area. They could assist in the marketing of MSC's services to the employer, create links with both sides of industry, and help to educate the local working community in the abilities and potential of disabled people.

New Committees for Employment of Disabled People (CEDPs) will cover the same areas as MSC's 88 new District Manpower Committees. The role of the CEDPs will be primarily to survey and stimulate the provision of services for disabled people and so assist MSC more comprehensively in the development of its services.

The work of the CEDPs will be carefully monitored and will be reviewed at the end of 1982. During its review, the Advisory Council consulted a wide range of organisations.

Special course still open

APPLICATIONS are still welcome from professionals such as physiotherapists and social workers for a course on spina bifida and hydrocephalus which is being held in Sheffield from April 6-8.

The programme is a fairly comprehensive review of all aspects of spina bifida and hydrocephalus, including prevention, antenatal diagnosis, neonatal assessment, varieties of treatment of spina bifida and hydrocephalus, social problems, adolescence, the urinary tract and orthopaedics.

For more information contact Mr A E MacKinnon at the Children's Hospital, Sheffield S10 2TH. Tel: 0742 71111.

What about the 1970 Act!!

A GROUP of national charities including ASBAH has joined forces to fund a three month project to assist disabled people to obtain the help they need under Section 2 of the Chronically Sick and Disabled Persons Act 1970 and related legislation.

A number of local authorities are either: refusing to assess the need for a service; failing to provide a service after accepting need; withdrawing a service where need has not diminished.

In particular, authorities are refusing or withdrawing a service when a disabled person is unable to meet a new or increased charge. Lawyers have advised that such action is illegal.

The project will be undertaken by Mrs Ursula Keeble, a social worker and author of 'Aids and Adaptations' (Bedford Square Press, 1979).

She is anxious to hear from anyone who feels that their local authority has not given them the kind of help provided for in the 1970 Act.

Further information from Beverley Holland at National Office or Mrs Ursula Keeble or Mr Peter Mitchell, RADAR, 25 Mortimer Street, London W1N 8AB. Tel: 01-637 5400.

Motability clocks-up 10,000 cars

A SPECIAL ceremony took place outside 10 Downing Street on November 19 to mark the 10,000th car in service under the Motability scheme.

The Prime Minister, Mrs Margaret Thatcher handed over four cars made by British firms to four disabled people who had applied for them under the Motability Scheme.

Since its inception in 1977, Motability has approached all current recipients of Mobility Allowances (about 180,000 people), has provided 10,000 cars to disabled people. It has thousands more on the way.

Design—for the handicapped

A Register of Buildings has been set up by the Centre on Environment for the Handicapped. It features more than 500 buildings or schemes of all kinds in Great Britain which have been designed or adapted for physically or mentally handicapped people. Plans, photographs, briefs, reports and appraisals are available.

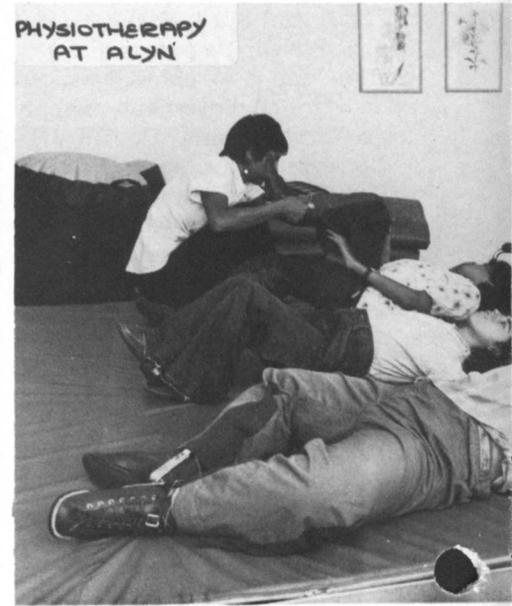
The Register was especially commissioned to interest and assist architects, voluntary organisations and local government departments in the adaptation of buildings, or the building of new premises.

For more information tel: 01-267 6111. CEH is at 126 Albert Street, London NW1 7NF.

REMAP grows and grows

The formation of REMAP panels all over the country continues apace. A new one is now in operation in Newport, Gwent and would welcome referrals from occupational therapists and others in the area. A panel has been formed in Northamptonshire, and plans were underway to start up in South Durham.

More details from Martin Marshall, REMAP National Organiser, Room 37, Thames House North, Millbank, London SW1P 4QG. Tel: 01-834 4444 ext. 4112.



OVER THE past few years the Alyn Orthopaedic Hospital Rehabilitation Center has developed into a national centre in Israel, for the medical, social and educational assessment of children suffering from spina bifida. The objective is the preparation of the child for a meaningful and independent life within his own family and community.

The severe handicaps created by spina bifida must be combated on two fronts: first, the child has to understand the limitations of his disabilities and to develop his physical and intellectual assets to the utmost; secondly, he has to overcome apathetic attitudes of the society into which he is born.

Our continuous effort is to maintain healthy motivation in the patient. It is a difficult task to give him the courage to adjust and to rise above his handicap.

Services to the severely handicapped are usually characterised by low expectation of development, and a general devaluation of the handicapped person.

The rehabilitation process of the severely disabled extends over a long period and needs to be intensive. Each rehabilitation programme must be planned on an individual basis *with* the patient and not *for* him. He must be regarded as an integral part of the plan. In spina bifida patients we deal with children who have never

been healthy. They start life with serious deficiencies, physical and emotional.

The children's needs are great and diversified and it is often difficult to expect a family to meet them. The problems faced by the small child and his family are relatively uninvolved, as all babies need daily care and treatment. As the child grows older his needs grow and remain complicated; the discrepancy between him and his peer group increases.

The disabled child needs to be involved in an active rehabilitation programme from the beginning. The treatment should be carried out on two levels: 1. The child: 2. The family.

The child usually undergoes a series of surgical interventions and active physiotherapy, as well as intensive occupational therapy, starting early in life. Once the diagnosis is made, the parents need to be told the truth about their baby and need the assurance that the hospital, with all its facilities and financial help, will stand behind them to help and guide them. When the child reaches kindergarten age he must be given the same opportunities as his healthy peers. He needs extra help, special gadgets and facilities. Independence can only be reached when facilities are freely available.

The programme for spina bifida patients who are incontinent needs constant review. This problem is

DURING International Year of Disabled Children, a number of articles about other countries associated with spina bifida. LINK between the Alyn Orthopaedic Hospital and Rehabilitation Center, written by the Centre's Director of Social Work, PSW. Founded in 1936 as a non-profit organization for handicapped children, Alyn has grown into an out-patients clinic. It's a bright, open Hills with an air of confidence it seeks

ISRAEL

often much more impairing for the rehabilitation process than the fact that the patient is paralysed. He may be rejected by his peers due to unpleasant odours and may suffer from urinary tract infections.

We have seen many children suffering from spina bifida who enjoy life in the kindergarten and are later able to follow a normal school programme. These are usually children who were given tremendous support by their families. Children who come from broken homes and/or multi-problem families show a much poorer emotional and physical performance. Many such children need to be hospitalized frequently, or even institutionalized.

No matter how well the child suffering from spina bifida is rehabilitated he will always have a different life-style from his peers. He will need more time to complete his daily activities such as



led People, LINK plans to carry a
ies and how they tackle the problems
gins its 'travels' in Israel at the Alyn
ion Centre, with an article specially
ocial Services, Tirzah Ilan, BAMSW,
it making clinic for physically
n into a modern 100-bed hospital with
pen place overlooking the Jerusalem
s to pass on to the children.

washing, dressing etc. Urine and
bowel routine may be time
consuming and a nervous strain.
There is always the worry of
accidental leakage of urine and
bowel movement during the day,
which causes social
embarrassment. His diet, his liquid
intake is increased.

Architectural barriers are a
problem. Housing designed for the
disabled is still scarce; he must
overcome countless flights of
stairs, narrow doorways,
unsuitable toilets and rest rooms.
In recent years, in Israel, there has
been some improvement regarding
housing for the disabled, as well as
increased accessibility to public
buildings. Although there is as yet
no law in Israel that compels
employers to hire handicapped
people there has been improvement
in this field. Through the efforts
of the Alyn Hospital many
government and private offices



have begun to hire the
handicapped. We have also found
work for the handicapped as
factory workers and telephonists.

When the severely handicapped
person has no family to lean on he
has to travel the long road of
rehabilitation alone. This may
hamper him and at times even
prevent his rehabilitation. In such
cases, close contact between the
social worker and the handicapped
person is essential.

In 1972 Alyn started a housing
programme for severely
handicapped young people who
had been institutionalized and
could not return to their families
or communities. With the help of
the Ministry of Housing, flats were
purchased in the community.
These flats, which are adapted to
the needs of the occupiers, are
usually shared by two people. Alyn
helps to furnish the flats and
acquire the necessary equipment.

The young people can decide for
themselves with whom they will
share the apartment. They are all
employed and drive their own cars.
All the flats have three rooms,
which enables the young people to
have privacy in their own room,
yet not be lonely. In our opinion
this is the ultimate in rehabilitation
and enables even the severely
handicapped person to live a fairly
normal life sharing the
responsibilities and privileges of
the community and becoming an
independent and useful citizen.

Clinics:

Alyn has a large weekly clinic for
children suffering from spina
bifida. The purpose of the clinic is
as follows:

1. To provide medical and social
assessment of the child living at
home.
2. To arrange hospitalization when
medical treatment is required.
3. To arrange institutionalization
when the child cannot receive
treatment or education at home.
4. Finding and developing
alternative community services
of care and training, to prevent
hospitalization.
5. To provide after-care services
for children, who have been
hospitalized and discharged, by
a multidisciplinary team
consisting of doctor, public
health nurse, social worker,
physiotherapist and
occupational therapist.

During the year 1978-1979 the
clinic at Alyn has seen and treated
about 4,000 patients.

TIRZAH ILAN

Director of Social Services Alyn,
BAMSW PSW.



AS AN orthopaedic surgeon with a special interest in spina bifida, I have worked for many years with spina bifida children and their families and have got to know many of the families very well. Now many of the small children have grown through adolescence into young men and women, anxious to lead their own lives and make these lives as full as possible.

Whilst at school there are many problems to overcome, but the means of overcoming these problems is usually to hand. There are special schools for those who are unable to attend normal school and there is transport laid on. Mum is there to help with dressing, calipers, and managing incontinence; to do the washing and the shopping. Children are not involved in financial problems—although they are often present. At school one has friends to mix with and with whom one can share experiences.

Suddenly everything changes—it is time to leave school. No longer will everything be easily available; getting help becomes much more difficult.

In Newcastle, supportive treatment for spina bifida families is very good. We have been aware for some time that we would have a group of people who would need a special kind of support—those young adults handicapped by spina bifida.

Because of this we felt it would be wrong to wait until severe problems began to develop; we had to organise some system to support and help these young people from the time they left school.

Apart from the break from the protective school environment, there was the additional problem that many of the doctors who cared for them in childhood would be unable to continue this care after the young people reached the age of sixteen. There had to be someone, somewhere to whom they and their families could turn.

This was why I started our "Young Adult Clinic" over a year ago, with the help of Mrs Sylvia Hogarth the Senior Community Physiotherapist who also looks after the children in special schools. The initial attenders (aged 16–32) had already been visited by Miss Barbara Castrie, a medical student on a research programme,

Newcastle Clinic shows how young adults can be helped

by
B. J. ROBSON, MB, BS
Assistant in Orthopaedic
Surgery
Freeman Hospital
Newcastle-upon-Tyne

and we knew they were interested in such a clinic.

As well as the recent school-leavers we also take direct referrals from doctors, nurses, physiotherapists, social workers etc. It is the patients' choice as to whether they come on their own or bring parents with them.

The clinic is held in the headquarters of the Newcastle-upon-Tyne Council for the Disabled—Mea House—we suspected that most of our clients would have had enough of hospital clinics! Problems can be discussed with the panel as a whole or privately with any one of us, (including medical examination if necessary). There is plenty of room so those waiting can see the aids available and chat to each other. The accent is on *informality*. Access, including parking and lifts, presents no problems.

PANEL

There are five of us on the "panel"—myself, Sylvia Hogarth, Christine Tarling (Senior Occupational Therapist), Eric Spriggs (Disablement Resettlement Officer), and Angela Blenkinsop the Information and Advisory Service Officer. This panel can offer help and advice on the many problems which arise—related to health, splints, wheelchairs, jobs, finance, mobility and housing. If we cannot help directly we can put clients in touch with individuals or departments who can help.

Sorting out problems often requires more than one visit. When everything has been done that is needed, the clients can be

discharged or if they wish keep in touch at intervals. So far, nearly everyone wishes to keep in touch.

We have met and dealt with a multitude of problems in our first year—some were quite appalling. Some callers had only one problem eg splints; but some had many.

One young lady of 17½ came—she had weakness in her legs, a spinal curvature and a urinary diversion. She lived in a house with no hot water and an outside W.C. She was still wearing the ugly boots and short irons she had at school. She was on a further education course but had no job prospects at the end of it. Now the family have been rehoused, she is taking Civil Service Entrance exams with good job prospects and she has had her ugly apparatus replaced by attractive surgical shoes. Yes, surgical shoes can be attractive if you have a sympathetic doctor and shoe-maker. Certainly this young lady is one of our great successes.

What are the commonest problems we have to deal with?

Firstly, appliances and aids: many callers had ugly or unsatisfactory calipers and footwear, some no splintage at all. Everyone suitable was given cosmetic calipers and shoes. Many had unsatisfactory wheelchairs—some too heavy, some too small. They were referred to the Wheelchair Clinic—and have all been provided with chairs more suited to their needs.

Secondly, job problems: some had no jobs, some were in unsatisfactory jobs or in unstimulating day centres. The DRO arranged for some to go to training colleges and other further education establishments; others went into new and better employment.

Many had health problems—often to do with stomata—and needed referral to the Urologist. One or two had pressure sores needing hospital

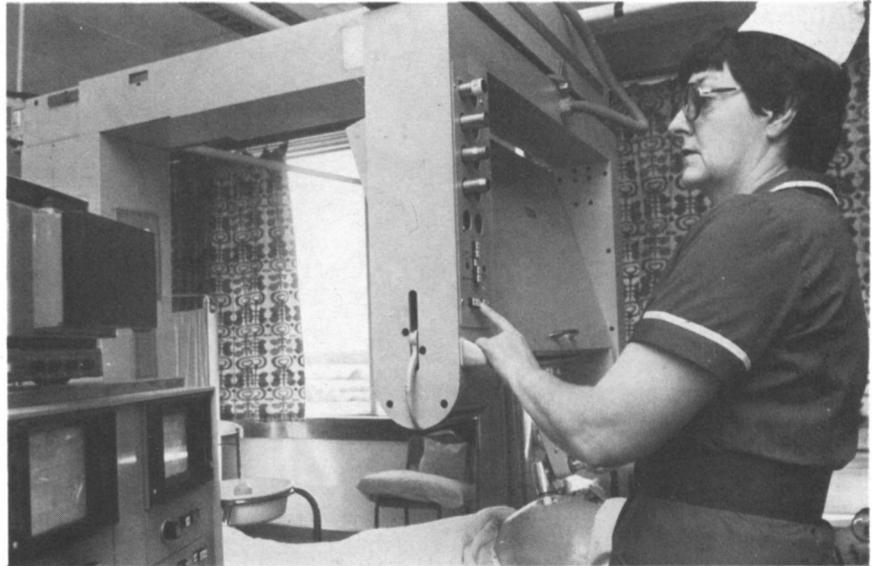


treatment. There were problems with knees and feet, dental problems—even one young man with severe acne. All have now received the appropriate treatment.

Some patients have needed rehousing, some have needed more aids at home, and for many we have arranged a full home assessment to be done. Financial problems, often due to ignorance of benefits, are quite common. Lack of social contact is another common complaint—and where possible, people have been put in touch with local groups to help them.

I believe that Newcastle is one of the first areas to run a clinic of this kind. I and my colleagues believe that we can offer help to young handicapped people and most of those who have come to us would agree with this.

I am sure our main difficulty is finding out who needs help. Let us hope that other areas will follow our lead and set up their own clinics to help this special group of people—the young adult disabled.



Ultrasonic unit—Sister Jean Lewis in charge

The current state of antenatal diagnosis

ANTE-NATAL screening by amniocentesis is a routine procedure for all pregnant women who have had a previous child with spina bifida or encephalocele or anencephaly (“neural tube defects”) whether the pregnancy

ended in a liveborn baby, a stillbirth, or an abortion—induced or spontaneous.

It is also essential if the mother or father has spina bifida, and desirable if there is a strong family history of spina bifida or anencephaly. The test is best done at 16 weeks of pregnancy.

The tests are available in every part of the country and every pregnant mother has the right to ask for it. No doctor is obliged to carry out such a test, but if he does not wish to do it, he ought to refer the patient to a colleague who does carry out such tests.

No expectant mother need accept a refusal to carry out the test. She has every right to ask for a second opinion and a referral to another consultant, expert in this field.

In many areas routine blood tests are carried out on *all* pregnant women at about 16 weeks of pregnancy. The results of these will show the need for amniocentesis in a small minority of pregnant women. Alternatively, ultrasonic examination of the uterus may show an anencephalic foetus. In such a case the pregnancy can be terminated without amniocentesis. Spina bifida can only be shown definitely by amniocentesis.

by Professor John Lorber

Maternity Alliance—a voice for pregnant women

A CONFERENCE was held in November to launch “The Maternity Alliance” a new organisation which aims to improve services offered to women during pregnancy, childbirth and the perinatal period.

The speakers at the conference were Mrs Renee Short MP, Chairman of the Social Services Committee which produced the report ‘Perinatal and Neonatal Mortality’ and Mr Geoffrey Chamberlain—Obstetrician at Queen Charlotte’s Hospital, London.

Mrs Short told the delegates that £25 million was required to ensure that all maternity units met minimum standards and to ensure the availability of sufficient staff to save life and to help prevent the birth of handicapped babies.

Mr Chamberlain called for the

right of women to be told what treatment they were being given and why, and for the involvement of Social Services as soon as a handicapped baby left hospital.

Maternity Alliance hope to set up regional groups which will campaign for improved health care in the community for pregnant women, including more welcoming antenatal clinics with fewer delays, improvement and expansion of special and intensive care for the newborn baby and greater recognition of the importance of community midwives and health visitors.

ASBAH is a member of this ‘Alliance’.

Anyone wanting further information should contact: Helen Hayman, The Maternity Alliance, 12 Park Crescent, London W1.

NAIDEXCELLENT! Naidex 1980 at the Cunard International Hotel was an excellently organised show, with plenty of space for exhibitors and visitors and more to see than ever before. It was a feast of new ideas, new aids and gadgets.

The cost of having a stand at the exhibition and staffing it is no small matter and ASBAH is grateful to the generous sponsorship of Britax. Staff on the ASBAH stand report that they were on their toes most of the time selling publications, appeals items and answering questions.

LINK has chosen to report on a few aids and manufacturers who were at Naidex. The products might be of particular interest to readers.

In view of the high cost of much of the equipment on display let's start with something that is free!

Aids for the Disabled: The new issue of this useful booklet was available at Naidex. It is a great improvement on the previous one and includes a list of Aids Centres, and Artificial Limb and Appliance Centres (ALACS) and information on where different kinds of aids can be obtained.

Copies can be obtained from local Social Security Offices or by post from DHSS (leaflets) PO Box 21 Stanmore, Middlesex HA7 1AY, or in Wales from the Welsh Office, Health & Social Work Department (LASS 3A), Pearl Assurance House, Greyfriars Road, Cardiff CF1 3RT.

Safety Cradle Seats.

Recticel have developed seats for children's swings. The basic seat is a hard-wearing rubber moulding bonded to a strong metal inner framework, and it includes a number of excellent features such as an impact-absorbing edging. The Gate Type Seat is ideal for use by handicapped children and a safety harness can be supplied for increased comfort and safety. Prices are reasonable. The Gate Seat costs £28.65. Recticel Ltd are at 22 Summerville Road, Bradford BD7 1PY. Tel: 0274 27370.

Handicapped Child Seat.

This car seat by **Britax**, which has been advertised in LINK in recent issues, attracted much attention at Naidex. It was

NAIDEX—new ideas aids and gadgets



Cindico's new 'Double Li-Bak Traveller'—a folding double pushchair which can take a handicapped toddler and a young baby. It is available through the National Health Service Wheelchair Service.

developed in consultation with a number of leading organisations concerned with the disabled including ASBAH. The aim was to create a car seat that allows individual adaptation to suit children with different needs. It is a good idea to ask your child's therapist for advice as to the suitability of the Britax Seat, and also about the need for padding.

Secura Bath Seat.

This is a reasonably priced and stable combined bath seat and board produced by **Nottingham Handcraft** in their Sunflower Bathing Aids. It is made from a strong slip resistant plastic material. Price: £14.06 each. Details: Nottingham Handcraft Ltd, 17 Ludlow Hill Road, Melton Road, W. Bridgford, Nottingham NG2 6HD. Tel: 0602 234251.

Bath Care Chair.

For the very severely disabled the Bath Care Chair by **Ortho-Kinetics** could prove useful. It facilitates the task of lifting, transporting and supporting the child in the bath, leaving the parents' hands free to properly wash the child and the child's hair.

The upholstery is of nylon mesh which dries very quickly. It comes

in just one size to accommodate a child of up to about 14 years.

Details from Ortho-Kinetics (UK) Ltd, Care Chair Division, 24 South Hampshire Industrial Park, Totton, Southampton SO4 3ZZ. Tel: 0703 863629. A representative will come and demonstrate the chair in your own home to ensure that it is suitable for your child.

Legmuff.

Dermalex have produced a leg-muff for wheelchair users—adults and children—made of pure wool on a synthetic backing, and covered with a shower-proof fabric. It is much more effective than just a blanket and once zipped up it stays well in position. It is fully 'hot' washable.

The same design is available with a much thinner wool pile lining, where less protection from the cold is necessary. This is only suitable for cold washing.

Prices for the children's sizes are £47.50 (plus VAT £7.12) for the thicker style, and £24.25 (plus VAT £3.64) for the thinner wool style. For adults the prices are £57.95 (plus £8.69), and £26.85 (plus £4.03). All prices include postage and packing.

Orders accompanied by a signed Doctor's Certificate are exempt from VAT.

Available from: Dermalex, 146/154 Kilburn High Road, London NW6 4JD. Dermalex have a well illustrated brochure of their full range of wool/nursing aids, including bed fleeces.

Bidet.

Nicholls and Clarke had a bidet on show which, although expensive, may be a necessity for someone who is doubly incontinent. It has a good, firm wooden seat and the spray is at the front, so you sit on it the same way as you would on a toilet.

Price: £74.82. Nicholls & Clarke are at 3/10 Shoreditch High Street, London E1 6PE. Tel: 01-247 5432.

Joncare products.

Joncare now cover a wide range of children's equipment and the

prototype of the new Flexistand Major standing frame was on show. It is superbly designed and will soon be available.

For details of Joncare products write to them at Meadjess Ltd., Radley Road Industrial Estate, Abingdon, Oxon. Tel: 0235 28120.

Carters expand.

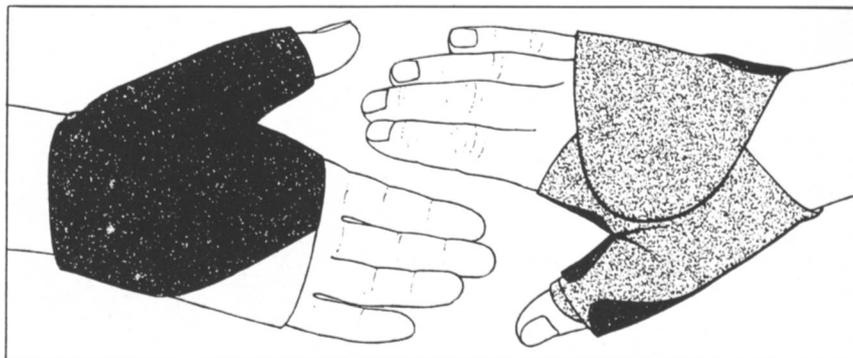
Carters have now expanded and represent EC Europe Ltd. They are now making Zimmer Wheelchairs under the Carters' name. Write for their catalogue to: Carters (J & A) Ltd., Alfred Street, Westbury, Wiltshire BA13 3DZ. Tel: 0373 822203.

Rifton Equipment.

The new catalogue showing the wide range of **Rifton** playgroup and school equipment for the special child is now available from Community Playthings, Robertsbridge, East Sussex, TN32 5DR. Tel: 0580 880626.

Play mobiles.

The bright and varied Play Mobiles produced by **Meyra Rehab** attracted much attention at Naidex. The design and construction is geared to providing



Wheelies are a new do-it-yourself glove for wheelchair users to protect their hands and give a better grip. They come in a kit with instructions and cut-out card pattern to tailor them to individual hands. They are made of leather, and can be worn over ordinary gloves, or on their own. Price: £5.75 including VAT and postage and packing from: Henry Beakbane, Wheelies, c/o Beakbane Ltd, POB 10 Stourport Road, Kidderminster, Worcs. DY11 7QT. Tel: 0562 745061. They can be bought from the Stoke Mandeville Stadium Shop, in which case the price will cover a tube of adhesive.

not only mobility and independence but enjoyment as well.

Marc, and Brigitte are two three wheeled bikes that might be suitable for a spina bifida child, and there is also Marie-Cecile, an interesting four wheeled play mobile. Write for the catalogue to: Meyra-Rehab UK, Millshaw Park Ave., Leeds LS11 0LR. Tel: 0532 776060.

* * *

Naidex '81 will be held at the National Agricultural Centre, Stoneleigh, near Kenilworth, Warwickshire from 21-24 October.

* * *

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THE RELIABLE SOURCE OF SUPPLY

EVEN THOUGH, at the time of writing, most peoples' thoughts are fairly occupied with Christmas, it has been a busy time for ASBAH's fund-raising staff.

MADELEINE LEGG, the Southern Area Organiser, has run a most successful charity gala night at Blazers in Windsor, with Danny La Rue as the star of the show. The event, which raised £3,000 for ASBAH, was very much enjoyed, particularly as we were able to offer tickets at the very affordable price of £8.50 which included a three course meal and the cabaret.

In these days when we are all counting the pennies one really has to try and offer value for money and I think that for ASBAH to have made such a substantial sum out of this event is most encouraging. It points the way to more events at this sort of price level, and you will receive advance information, in case you would like to join us.

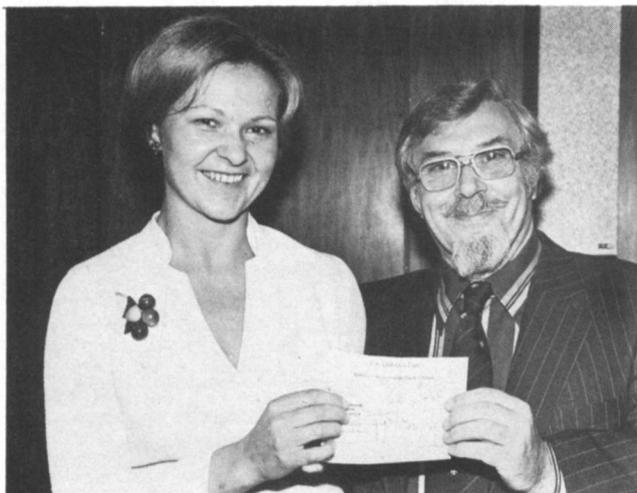
Madeleine was also to be seen at the Gatwick Park Hotel receiving a most generous donation of £1,189 from Mr Alf Evans. This money was raised as a result of a disco and wrestling contest held at the hotel.

On a more highbrow note, Mrs Legg also organised a concert at Guildford Cathedral, featuring the BBC award winning Reading Male Voice Choir with television personality Geoffrey Wheeler as host for the evening, although unfortunately this did not prove to be quite such a popular event as the concert by Danny La Rue!

THE EVER active Barry Mishon who, sadly, will be leaving ASBAH at the end of January, has also been very busy, as the following report from him demonstrates:

THE magnificent splendour of Drapers Hall in the City of London, was the setting of a most glamorous 'happening' in October—a Poetry Reading Dinner, the style of which was certainly different.

Prior to the dinner, there was a reception held in the only original part of Drapers Hall, dating back to the 17th Century, and once everyone had taken their



Madeleine Legg, ASBAH's Southern area organiser receives a handsome donation from Mr Alf Evans of Gatwick Park Hotel.

Photo: Gat-Pic

An Appeals Recipe

. . . gala nights and discos . . . wrestling and concerts . . . poetry and sporting dinners . . .

Christmas goodwill and a TV appeal to follow

places at the tables a fanfare by two state trumpeters heralded the celebrity hosts of the evening.

Some 100 people sat down, amidst the splendour of marble columns, painted ceiling and mirrored gallery, to an excellent candle-lit dinner, each table being hosted by eminent persons from the world of theatre, films, television. The hosts included: the ever young Lady Diana Cooper, David Bailey, Rowan Atkinson, Angharad Rees, Tessa Dahl, Jane Asher and Gerald Scarfe. The special guest readers of the evening were: Tom Adams, Edward Fox, Alan Howard and Gayle Hunnicutt, all of whom read extracts of poetry and prose of their own choice, during and after dinner.

Limited prints by Feliks Topolski, signed by him, were for sale, as well as Nanette Newman's latest book of children's sayings, each book having been signed by Miss Newman and Bryan Forbes, and donated for the evening by the publishers, Collins.

The best way to sum up the evening's success is to quote one guest who purchased two tickets principally because his daughter "wanted to meet Rowan Atkinson" and was "no lover of poetry"—"now, however, I am not only going to be a staunch supporter of ASBAH—but I am also converted to reading and listening to more poetry!"

BARRY J MISHON

MEANWHILE, in the Midlands, Jane Evans has been adopting a sporting format for her fundraising. She successfully enlisted the help of Nottingham Forest football team and a crowd of well-wishers who were prepared to pay £20 each in order to join the team, together with their manager, Brian Clough, and many other Midland sports celebrities, including Billy Wright, the first man to be capped 100 times for England, for a most successful dinner party at Nottingham's Commodore Club.

ASBAH's old friend Shaw Taylor was present and was successful in raising £300 by auctioning one of Billy Wright's caps, which was just one of the contributions which resulted in this event raising in excess of £2,500.

At a more feminine level, Jane has also successfully run two fashion shows and has some very exciting plans for fundraising events in the new year.

MR IAN Craig in the Yorkshire area has not been with ASBAH long enough to have organised any events as yet, but nonetheless, contributions are



Celebrities at the Drapers Hall—(left to right) Edward Fox, Alan Howard, Gayle Hunnicutt, Gerald Scarfe, Jane Asher, Angharad Rees, Lady Diana Cooper, Sir Charles Nightingale, Moyna Gilbertson (ASBAH), Tom Adams, David Bailey, Rowan Atkinson and Tessa Dahl.

Photo: Richard Young

already starting to come in as a result of his efforts and we hope that in the future the awareness of our organisation will be increased manifold as a useful by-product of the national fundraising programme.

LIFE IN head office at this time of year is slightly less spectacular, as this is the time when we write, once again, to all our very generous donors and I am pleased to be able to report that they have, as always, answered our call.

It is particularly touching to see how many old age pensioners send contributions at Christmas and a heartwarming example is of a husband and wife who sent us their Christmas increase in pensions. It is a time of year when one realises just how wonderful and how caring the British are and all of us on the

staff of ASBAH are working very hard to ensure that their generosity is used to the best possible effect.

PROBABLY the most exciting news which we have received since the last issue of LINK is that we shall be benefiting from a commercial television appeal during 1981. We really have been incredibly fortunate in having enlisted the help of Michael Aspel as our presenter for this appeal and this certainly goes a long way towards giving us confidence that the International Year of Disabled People will be a particularly successful time for ASBAH. We are all looking forward to one of our best years ever and I would like to wish you the same.

JUDY KAY



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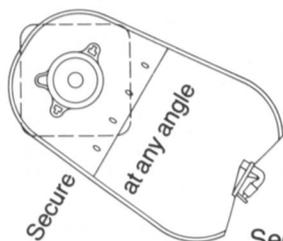
welcome to a world of independence

New for Urostomy!

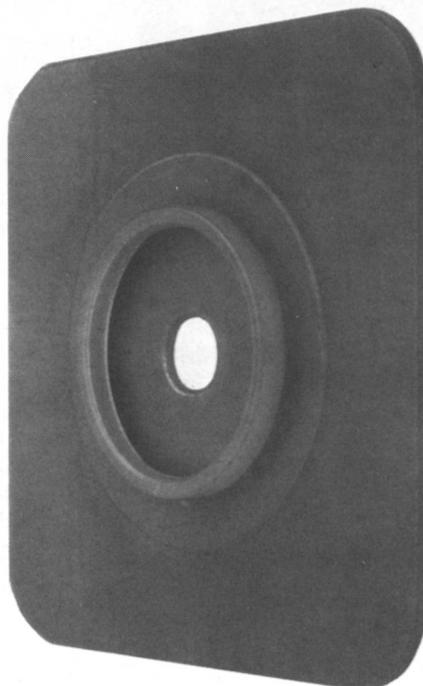
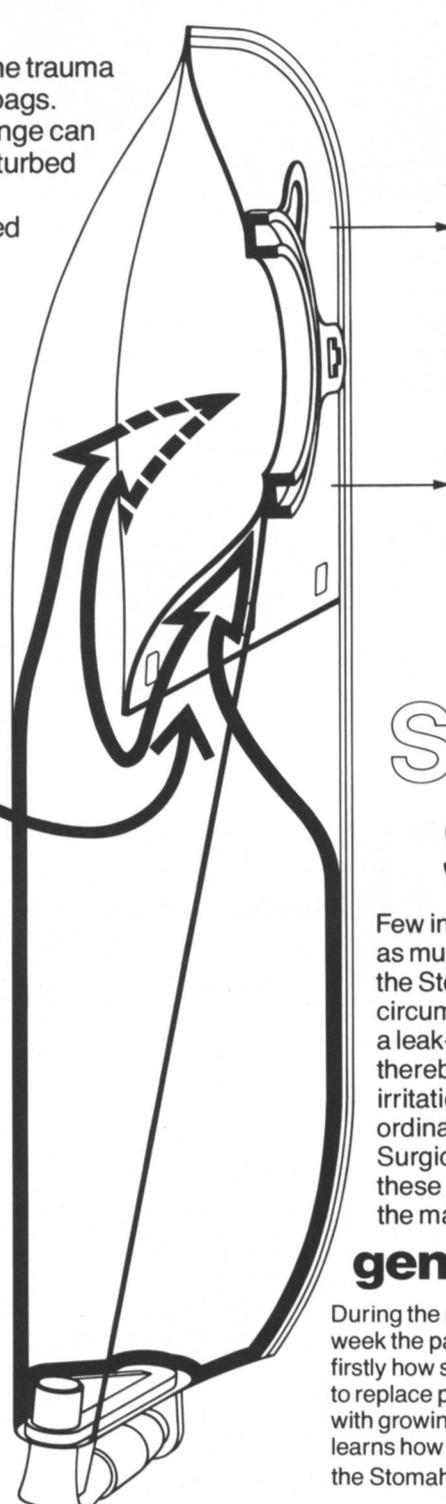
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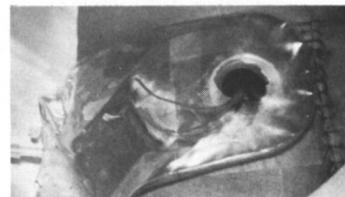
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Please send remittance with your advert.

Adverts for the next LINK (March/April) should be in by February 10. Send to the Editor Mrs Susan Gearing (or telephone her on Langton 3351).

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London Holiday Flat: London, N4.

Motor Caravan: First season 1981. Can be hired for one or two weeks, and driven anywhere in Gt. Britain. It has tail lift, special wheelchair W.C./Shower unit, and other modifications. Black & White T.V. and Radio.

For further details contact: John Grooms Holiday Department (Ref. L1.), John Grooms Association for the Disabled, 10 Gloucester Drive, London N4 2LP. Tel: 01-802 7272.

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