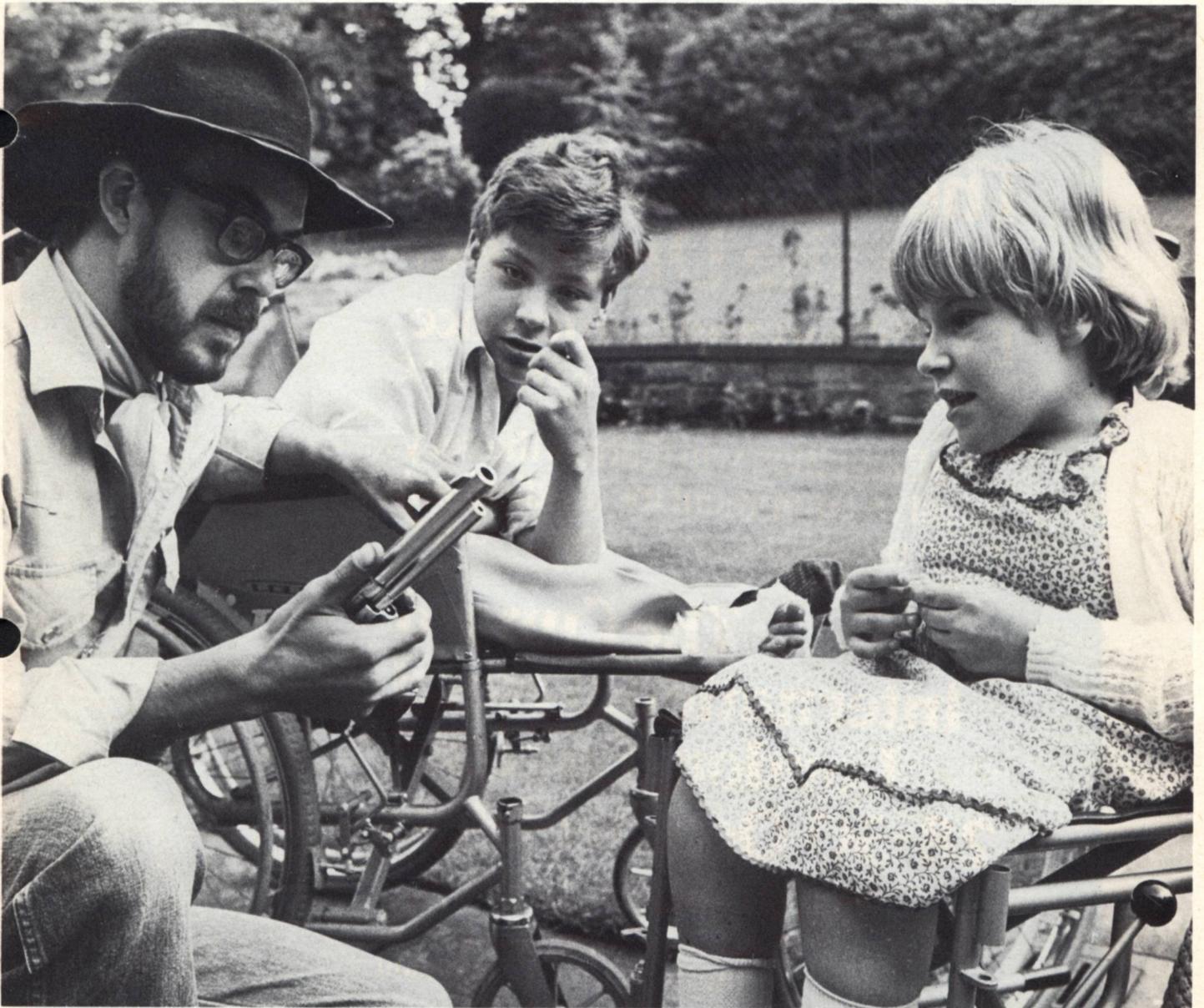


Link



Association for Spina Bifida and Hydrocephalus/ASBAH 15p

Sept/Oct 80



IN THIS 24 PAGE LINK . . .

**Planning for IYDP: Asbah Conference returns:
Cowboys and Indians at Five Oaks: The benefits of music:
Looking at co-operatives: Personal story from Sweden**

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LINK 70

naidex '80



The National Aids for the Disabled Exhibition and Conference

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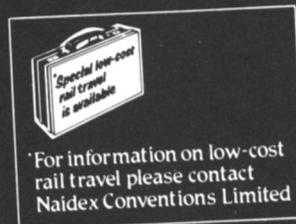
The Exhibition will feature the very
latest in equipment for the disabled
from more than 150 manufacturers

**The Cunard
International Hotel
London, England
28-30 October 1980**

Free Admission to Exhibition

The Conference will be held at
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Link ⁷⁰

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.

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Finance Officer:

Mr F G Armour, FCA

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Mr H Croydon

Education, Training & Employment

Officer: Mrs B Newman

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Information Officer:

Miss B Holland

LINK Editor:

Mrs S I Gearing

New 24 page issue!
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ONE OF the most important roles of National ASBAH is to monitor legislation, and to make comments. Sometimes ASBAH comments independently, and at other times along with other organisations with similar concerns.

The past year has been a particularly busy one. The Leader of the House of Commons, Mr Norman St John Stevas, has said that the Government has now put through almost three quarters of the legislation promised in the Conservative Manifesto. Much of this has had some implication for ASBAH.

Of particular importance are the Education (No. 2) Bill, and the Social Security (No. 2) Bill.

It is also two years since the Warnock Committee reported on special educational needs, and as LINK goes to press the discussion document—the White Paper ‘Special Needs in Education’—has just arrived at National office.

The Paper opens with a statement about the present position:

‘The education of handicapped children, now a well-established part of the education service in England and Wales, was thoroughly reviewed by the Warnock Committee. The Committee’s report is a landmark in the development of policy and practice in this important area. The Government has decided to reform the law in the light of the Committee’s findings.’

The document continues with details of the Government’s views and proposals. Because it is such a detailed document it is not possible for us to discuss the subject more in this issue. However an article will appear in the next LINK. ASBAH has been invited to reply to the White Paper and is taking up the invitation.

GOVERNMENT watching over the past year has been a sobering task. In their manifesto, the Conservative Party promised to work towards a coherent system of cash benefits to meet the cost of disability as soon as the economy allowed. In the event, the government has decided that the economy does not allow—at least yet awhile.

Local authorities were asked to make real cuts in their expenditure. Most responded and support services for the elderly and the disabled were among the worst hit.

Nearly 30 per cent of disabled people live on their own. If local authorities cut, or increase charges for services it may become impossible for some of them to go on living independently. The only answer then would be for them to be institutionalised, and ironically, that would end up costing the community much more money.

In November there will be increases in the rates of some benefits such as Mobility Allowance and Attendance Allowance, but the government will no longer have to uprate long term benefits in line with prices and earnings, only with prices. If the pattern of recent times is followed, this means the disabled will lose out.

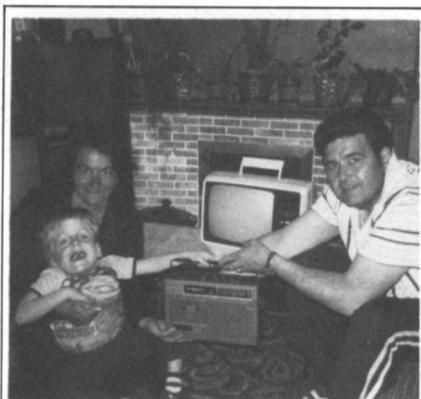
There are other ways too in which changes in policy have affected, or will affect, disabled people.

No one can dispute these are difficult times. But the help which is given to disabled people is often a solid investment. It can contribute to the independence of the disabled person. It can also save the community money in the long run.

FRONT COVER: Straight from the cowboy’s mouth . . . Two youngsters at Five Oaks with one of the cowboys who paid them a visit (see page 11).

Photo: Richard Young

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.



RICHARD Page (above) is feeling fitter and NASBAH, Surrey is the proud owner of a portable television and a radio cassette thanks to a sponsored slim which Richard undertook recently. Altogether he raised £127.

The television and radio are for NASBAH's mobile home at Selsey, Sussex, and the picture shows Richard presenting the gifts to NASBAH Secretary, Mrs B. Blackmore and one of the children, Philip Holmes.

Money for research

A CHEQUE for £1,400 for research was presented in July to ASBAH as a result of the fund-raising efforts of the Sutton Coldfield Soroptimists during International Year of the Child. Members all turned their hand to something to raise the money. They held coffee mornings, cheese and wine evenings and even an obstacle race for children. The money was received on behalf of ASBAH by Dr Jennifer Gray of Birmingham a member of the Midland Association (and mother of LINK's cover star of the last issue!)

Booklet

Your Child with Spina-Bifida by Professor John Lorber has now been reprinted and copies can be obtained from National Office (see p.22). ASBAH regrets that the price has had to be increased to 35p. Special rates are available to Local Associations.

Annual Meeting

ASBAH's Annual General Meeting. October 11. Westminster Cathedral Conference Centre.

ASBAH is very honoured that Her Royal Highness the Duchess of Gloucester will be with us at the Annual Meeting this year. The Duchess will be attending the morning part of the meeting, and will stay for lunch, which will be an informal buffet.

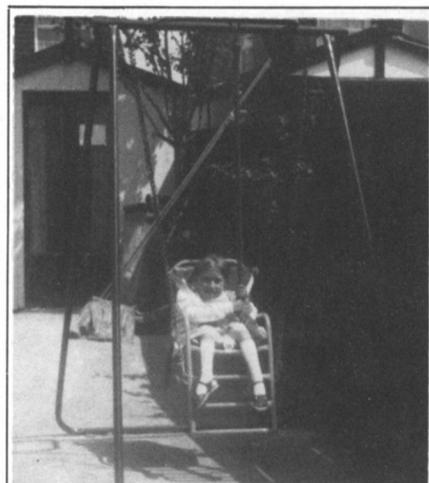
Our President, Lord Maybray-King will spend the whole day with us. So, too, will our Guest Speaker, Mr Peter Bottomley, MP.

We hope that many members will have the opportunity of meeting our distinguished guests.

The proceedings will start at 11.30 am. Coffee will be served from 10.30 am, and everyone is asked to be seated by 11.15 am ready to greet Her Royal Highness.

The Westminster Cathedral Conference Centre is a few minutes from Victoria Station, and there is a 24 hour car park nearby. But most important of all, the centre is completely accessible to wheelchairs.

We hope to see many members and friends at the Meeting, full details of which will be sent out with the official papers.



SUSAN Limburn of Prestatyn, Clwyd, is pictured above, in her specially made swing which she can operate herself on swing-boat lines.

Susan's mother wrote to LINK about the swing which she says has made her 9 year old daughter completely independent once she is on it. 'She is paralysed from the waist down, and so when she's on an ordinary swing someone has to push her.'

It was made by welder, Mr Philip Morgan at a cost of £128 plus VAT. Mr Morgan says he can adapt a swing for any age from a tiny child to a youth.

If any other readers would like to have more details Mr Morgan can be contacted at Prestatyn 89237.



Hastings aims for £15,000

THE HASTINGS Branch of Sussex local association is having a fund-raising drive to raise £15,000. Some of the money will be used to buy and adapt a mobile holiday home, and some of it will also be invested to help meet the needs of the families in the area. The drive started in March and so far over

£2,000 has been raised. Events have included an exhibition of paintings, a fashion show, a shop and a sponsored tramp to Eastbourne with local army cadets and the Mayor of Hastings, (pictured above).

Photo: Derek Casper, Hastings News.

International Year of Disabled People

A great boost to the plans for IYDP was the announcement in the Summer that his Royal Highness the Prince of Wales has agreed to become Patron of the IYDP Committees of England, Northern Ireland, Scotland and Wales.

And the Committee was also able to announce that Kit Aston, Founder and Chairman of the Disabled Sports Foundation, is to be Chairman of IYDP for England.

The IYDP Committee publicises the existence of the Year and its aims, but it is the responsibility of every individual and society to follow up awareness of the Year by getting across their own special needs and priorities.

There is to be no national IYDP Fund. This leaves societies free to raise funds for their own priorities.

The Year has four main aims * Increasing awareness of the needs, abilities and aspirations of disabled people * The participation, equality and integration of disabled people * The prevention of disability * More positive attitudes towards disabled people.

As it is a Year of Disabled People, it is up to groups of disabled people such as local associations of ASBAH to put on activities in the Year that support those aims, and are most appropriate to the area and its needs.

Joining together

Local Associations of Disabled and Councils of Voluntary Service (CVS) have been asked to bring local disability groups together to make plans for the Year. Make sure your group is included in meetings and contributes its ideas and suggestions. If you are as yet unaware of activities for the Year in your area, please contact the Local Association or CVS to see if anything is being planned.

Publicity

Make the most of the Year by publicising what your group does and the special needs of its members. Publicise your activities in 1981 as being "in the International Year of Disabled People", and use the logo.



Whenever taking up an issue, lobbying, or writing to a local paper, stress that 1981 is the International Year of Disabled People.

Because of the Year, the press will give more coverage to disability issues in 1981, making the Year an opportunity for all groups to get their own messages across. Our target should be not only the general public but also those who influence opinion (like local media) or take vital decisions (MPs, councillors, major employers) affecting disabled people.

Activities

Organise any activities that support the aims of the Year, particularly those which enable disabled people to be more involved in everyday life and will be of lasting value. Events should involve disabled and able-bodied people. For the sake of participants, they should also be enjoyable! Plans by local groups so far include special exhibitions, approaches to local organisations urging them to open up leisure activities and employment opportunities to disabled people, providing speakers to local societies and schools, access campaigns, and lobbying MPs and councillors.

IYDP is the best opportunity ever to get through the barriers of public indifference and ignorance to the lasting benefit of all disabled people. Let's make the most of it!

ASBAH will be pleased to hear from local associations about any plans they may have for IYDP, and in particular to hear from members who are acting as local co-ordinators for the Year.

Young people plan

The first conference to be held in this country in preparation for the International Year of Disabled People took place on the weekend of 18th to 20th April this year, at Goldsmiths College, South East London.

The conference, entitled 'From School to What?' was designed to give young people, both physically handicapped and able bodied, from all over the country an opportunity to meet and discuss the problems they were likely to face on leaving school.

More than 160 delegates attended the conference and the contingent of approximately 90 disabled delegates included many LIFT members.

The conference was organised jointly by ASBAH, ICAA, Oxfam, The Spastics Society, SOS, PHAB and RADAR, and was chaired by Miss Margaret Morgan of The Spastics Society. Speakers included Mrs Claire Short, Director of Youthaid, disabled mountaineer Mr Norman Croucher, OBE, member of the National Committee of IYDP, and representatives from the Careers Service, the National Association of Youth Clubs, and Friends of the Earth.

An exhibition including representatives from industry and voluntary bodies ran concurrently with the conference, and a variety of leisure activities was available to delegates.

At the end of the conference the regional groups presented their plans for community based projects, which included: surveys of buildings and local services; the provision of information; leisure facilities; attitudes towards and integration of handicapped people.

The projects are being carried out by Action Groups made up of delegates and other interested people in their home areas, and are funded by a £3,000 grant from the Royal Jubilee Trusts.

If you would like to join the action group in your area, or would like more information about their projects, please contact Christine Barlow at National Office.



In the thick of it . . . young people at the "From School to What?" conference. See report, Page 6. Photo: Spastics Society.

•STOP PRESS

Thanks to the national media most of you will have heard that the long awaited Cross Channel Parachute jump in aid of ASBAH took place at the end of August.

A full picture story will appear in the next LINK.

Safely supports a handicapped child.

The Britax Handicapped Child Seat has been developed to meet the needs of the handicapped child. The seat will safely support a child weighing between 20 and 100 lbs. And allows for individual adaptation to suit children with a wide variety of special needs.

The seat design is the result of co-operation between organisations like the Spastics Society, The Wolfson Centre, The Association for Spina Bifida and Hydrocephalus and Chailey Heritage.

Head supports, side supports,ommel and harness are fully adjustable, so the seat grows with the child. It's easy to install and remove, and it looks good too.

If you'd like more information about the Britax Handicapped Child Seat contact: Britax, Chertsey Road, Byfleet, Surrey KT14 7AW. Telephone: Byfleet 41121. a BSG International company



Shell. Fully stressed seat in glass fibre. Slots in seat back allow re-positioning of harness.

Cover. Navy blue. Deep foam-backed in wipe clean brushed nylon.

Head Supports. Foam with washable nylon cover. Adjustable vertically.

Side Support Pads. Two polystyrene inserts for support where required.

Pommel. Firm foam ring in washable nylon. Secured by Velcro.

Harness. Easy clean 1½" gold webbing. Safety buckle. Fully tested and BSI approved. Special adjusters make seating simple.

Swivel Fitting. Seat can be unclipped and swung to one side for easy entry and exit.



Britax
The experts in safety.



A smile for LINK from swimming Champion, Sharon Munton. We reported in the last issue that Sharon who has spina bifida had set up a new national record for the 25 metres breaststroke. Unfortunately this evocative picture arrived after the last press date.

New organisation to be launched

THE MATERNITY Alliance aimed at improving services for pregnant women is to be launched in November 1980. It is hoped to highlight the need for improved work conditions for pregnant women and the financial plight of many young and poor mothers, which must be alleviated by more generous social security provisions.

The Alliance will also research and publicise information about the damaging effect on the foetus of various agents such as lead, drugs, alcohol and tobacco. For further information contact Helen Hayman, Maternity Alliance, 12 Park Crescent, London W1.

Wheelchair cushions under examination

THE DHSS, in Association with the Westminster Hospital, is carrying out an evaluation of wheelchair cushions and would like your help.

Information is required about any cushion other than the standard DHSS foam, but especially about Roho, Spenco Gel, Cubex, Western Medical, Talley Ripple and the Deelon/Ortherton/T. Foam cushions.

So if you:

- sit in a wheelchair for more than 30 hours a week;
- have recent experience of cushions other than DHSS foam;
- live within the Greater London Area;
- would be willing to be interviewed about your cushion experience,

then Miss J. Sutherland, O.T. Department, Westminster Hospital, Dean Ryle Street, Horseferry Road, London SW1, would like to hear from you. Please give details of your cushion, home address and telephone number.

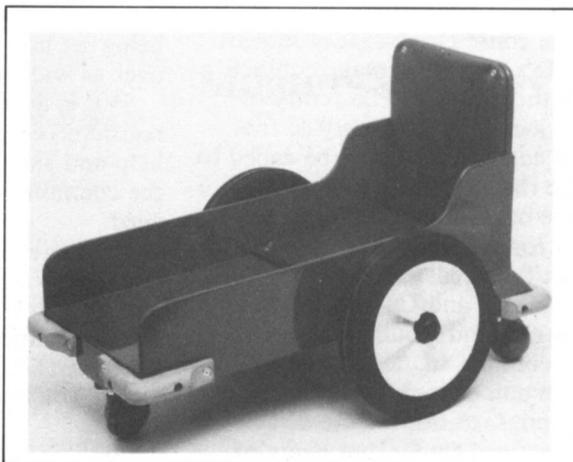
Designed specifically for the Spina Bifida child



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 PVC upholstery with the frame in chrome or red enamel.



The Newton Trolley is suitable for Spina Bifida children up to 10 years. A robust, manoeuvrable exercise trolley which allows a child to play with toys at floor level. Strong timber finished in non-toxic paint, with PVC upholstered seat cushion and back rest, and rubber bumpers. Fitted with two 10" (254mm) wheels, central castor at front, counterbalanced with two castors at the rear for safety. Seat width 10 1/2" (267mm). Seat depth 23" (587mm).

For further details contact:

Newton Aids Ltd

Dept. N57 L

FREEPOST (no stamp required)

Salisbury SP1 2YZ

Telephone: 0722 20441

When only the best will do — go Newton

Opportunities at the Co-op

CO-OP societies would welcome much more participation from, and contact with, disabled people. This was one of the messages put across at a special Conference on the Needs of Disabled and Handicapped People in the Community, organised by the Education Department of the Co-op Union (the federal organisation of High Street Co-op Societies) in the Summer in Leicestershire.

Disabled people and representatives of organisations concerned with the disabled attended, free of charge, for the week. It was part of the 'Co-ops in the Community' campaign being waged by the Co-op Movement.

Co-op societies—which are owned and controlled by members—offer plenty of opportunities to disabled people, who could stand as society directors and help to make the society really responsive to disabled consumers and members needs.

The conference urged disabled people's groups to make contact with the Education Secretary of their local Co-op Society so that local conferences could be called to make the general public more aware of disability. There was a need for training of co-op staff about the needs of disabled consumers, and Co-operatives Women's and Youth groups could help compile an Access Guide, where non existed, and review Co-op store facilities for the disabled.

For more details and name of your local society contact: Angela Hardy, Education Dept., Co-operative Union Ltd., Stanford Hall, Loughborough, Leicestershire LE12 5QR.

Motorway services

THE JOINT Committee on Mobility for the Disabled has asked ASBAH to let them have any information relating to inadequate provision for the disabled at motorway service areas. So please do let National Office know about your experiences!



This ambulance is on offer

THIS specially adapted ambulance of the Society of St Vincent de Paul (SVP) is available to groups of disabled people for outings and trips of all kinds, and holidays. It can cater for the more severely disabled.

A network of people who form the Friends of the Ambulance is being set up to promote the service over as wide an area as possible.

SVP is an international registered charity offering practical help and support to anyone within the community whatever their need.

For more details of the ambulance contact: The Transport Controller, 1 Birch Rd., Heatherlands, Headley Down, Bordon, Hants. (Tel: Headley Down 714087)

RADAR wants to hear about schemes

RADAR (The Royal Association for Disability and Rehabilitation) would like to hear from disabled people and employers who have benefited from the Manpower Services Commission schemes which provide funds to modify premises for a disabled employee.

Please write to Bert Massie at RADAR, 25 Mortimer Street, London W1, telling him about the kind of help received and how quickly it was provided. He would also like to hear if any assistance has been refused.



Chance to learn about aids

RELATIVES of handicapped children and professionals of all kinds are invited to an intensive day course, 'Aids and Equipment for the Handicapped Child', to be held on Saturday December 6 at the Frederick Holmes School for the Physically Handicapped, in Hull.

The course will cover a broad range of technical aids, equipment and techniques developed for physically and mentally handicapped children. It has a practical emphasis and opportunity will be given for discussion and to try equipment.

Fees (to include lunch and refreshments): £7 professionals; £5 relatives and non-professionals; £4 members of 'Active'. For more details: The Headmaster, Frederick Holmes School, Inglemire Lane, Hull, HU6 8J. Tel: Hull 854538.

Coming up to date on spina bifida and hydrocephalus

SHEFFIELD Children's Hospital is running a course on spina bifida and hydrocephalus in Sheffield, April 6-8, next year and one of the speakers will be ASBAH's Chief Executive Officer, Miss Moyna Gilbertson.

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

It is likely to be of interest to social workers, physiotherapists and indeed anybody in the paramedical profession concerned with these problems. Details of course fee from, and applications to Mr A. E. MacKinnon, Children's Hospital, Sheffield S10 2TH.

Facts on repair of wheelchairs

IN A LETTER to the Joint Committee on Mobility for the Disabled, the DHSS state that they are concerned at the 'serious misunderstanding' about the arrangements for repair of wheelchairs.

The letter points out: 'The arrangement is that for a repair costing £6 or less, the user can make his own arrangements and the Artificial Limb and Appliance Centre will foot the bill. For repairs costing more than this the user can contact the ALAC or the approved repairer at his own discretion . . . The approved repairer carries out repairs without submission of an estimate, providing the labour charge will be less than 2 hours (4 hours for powered wheelchairs).'

The Joint Committee was also told that an approved repairer has now agreed to call on a disabled person without first receiving a letter from the Appliance Centre.

Any information on problems relating to wheelchair repairs should be sent to ASBAH National Office who will pass them on to the Joint Committee.

AFTER an absence of a year, ASBAH's Spring Conference is to return in 1981. It will be held at Goldsmith's College, in the New Cross area of South London, from 10-12 April, and the programme will be relevant to the International Year for Disabled People (IYDP).

There will be particular emphasis on the work of ASBAH and its role in the 1980's.

Among the distinguished speakers who have confirmed that they will be attending are Professor R. W. Smithells, and Mr Roger Bayston, telling the conference about their research projects.

Full details of the speakers, and a Conference programme will be published in LINK.

Access at Goldsmith's College is good, and there are parking facilities.

Positive or negative?

THE THEME of this year's Naidex Conference is 'Disabled People—Positive Living or Negative Existence?' It will take the form of six separate seminars: Travel and transport; Co-ordination of Housing, Health and Social Services; Back Pain; Counselling and Disability; Returning Disabled People to Work Quickly; and Residential Care.

The venue will be Kensington Town Hall from October 28-30.

The Exhibition, held at the same time, will occupy 800 square metres of stand space at the Cunard International Hotel. So far more than 120 companies and associations are participating.

Access to the hotel is good and there are lifts to all floors. Disabled car parking is being arranged and the hotel is situated close to the M4. British Rail will again provide low cost fares to London.

For more Conference details contact: The Conference Officer, RADAR, 25 Mortimer Street, London WIN 8AB.

Tell us more about the older ones

I FELT I had to write and let you know how much I had enjoyed reading about Avril MacDonald and Susan Seagar in the May/June issue of LINK.

I am a spina bifida, aged 36, so you see I have a lot in common with both Avril and Susan. I am confined to a wheelchair but have a part-time job in the local Health Centre working mostly on the switchboard.

Recently I have started to learn archery in my spare time and very much enjoy the sport.

Please let us hear more about the older spina bifidas. I am sure even the youngsters would be interested to hear about them.

Daphne Cullen (Miss)

Felpham,

Bognor Regis, West Sussex.

'That's me—in Mummy's tummy'

MY SECOND daughter had spina bifida and anencephaly, and, after she died, we were very grateful to be offered the chance of an amniocentesis. Your article in the July/August issue of 'LINK' followed my experiences very closely, but for one detail.

The consultant had a camera attached to the screening apparatus and took some fast-developing photographs of the baby to put in the files. When I asked if I might see them, he quickly took an extra one which he gave me to keep.

It now has a very special place in our family album, with four-year-old Beth able to tell her friends: 'And that's me in Mummy's tummy!'

May I just add, too, how very kind the nurses and doctors were at the birth, fully appreciating the anxieties my husband and I felt and then happily joining in our great delight when Beth was born safe and well.

E. Joy Hillman

Hitchin

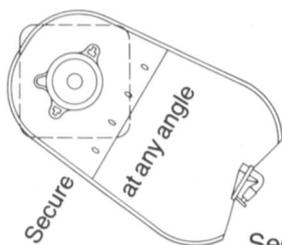
Herts.

New for Urostomy!

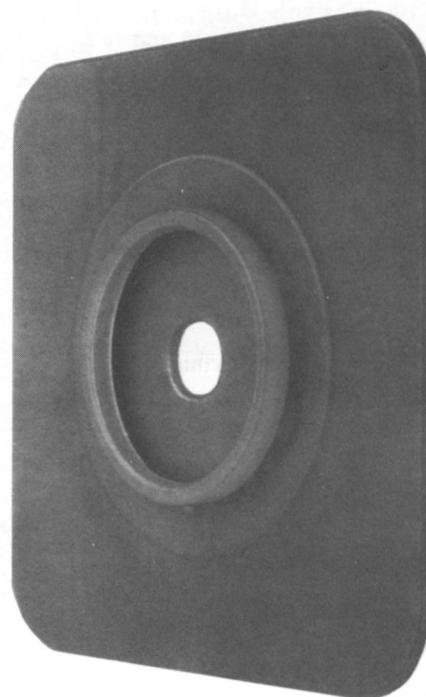
a new standard of comfort and security

Surgicare™ System 2 saves the patient from the trauma of peeling off adhesive bags. The Stomahesive™ Flange can be left on the skin undisturbed for several days whilst the pouches are replaced as often as necessary.

The non-return valve permits easy access of urine to the lower part of the pouch and efficiently prevents the return of urine to pool in the area of the stoma thus the Stomahesive™ wafer is protected from the breakdown effects of urine and therefore remains secure and leak-free for several days.



Secure closure: easy drainage



SURGICARE

Trademark

System 2

Few innovations in the last decade have contributed as much to stoma management as the introduction of the Stomahesive™ wafer. Even in the most adverse circumstances, the Stomahesive wafer makes possible a leak-free attachment of appliances to the skin thereby providing a unique degree of comfort free of irritation and soreness often associated with ordinary adhesives.

Surgicare™ System 2 takes full advantage of these benefits which are particularly evident in the management of urostomies.

generates confidence

During the post-operative week the patient learns firstly how simple it is to replace pouches, then with growing confidence learns how to prepare and apply the Stomahesive™ Flange.



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Regal House
Twickenham TW1 3QT
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Address your envelope to **Squibb Surgicare Limited, Freepost TK 245, Twickenham TW1 1BR**

Name BLOCK CAPITALS

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A 'pow-wow' on the lawn at Five Oaks

THE PAST few weeks have seen some new and varied activities within the Appeals Department and we are certainly most fortunate in having gained the help and friendship of some very talented and influential people.

ON THE FIRST Sunday in August, everyone at Five Oaks, in Yorkshire, was very excited at having some 20 cowboys and Indians descend upon the Home to meet the children and spend a few very happy hours with them.

The cowboys and Indians actually came from Bury and their leader is Don Fido. They have adopted ASBAH as their Charity and all the money that they raise from appearing at fetes, carnivals, pubs, etc will be donated to Five Oaks.

In May of this year they presented ASBAH with their first cheque for £1,250 and are hoping to exceed this sum in the coming year.

They were very interested to

Picturing the Cowboys and Indians

meet the children and to see the home. What they saw has given them an even greater incentive to raise as much as they can.

The photograph on the front cover and those on this page were taken by Richard Young, who is proving to be one of the top social photographers in this country. He has been the subject of various articles and seldom a day passes without his work being seen in the national press. A book of his photographs and anecdotes is due to be published in 1981.

Richard has also adopted Five Oaks as his special Charity. He is having a special exhibition mounted by Olympus Camera Centre, in the Ritz Colonnade, Piccadilly, London on January 5 for six weeks, and has most generously agreed to all the net proceeds being donated to Five Oaks.

He, like the cowboys and Indians, was pleased to meet the



This cowgirl's ready for action

children and see Five Oaks for himself, having taken time out from his very busy schedule in order to be there.

We really are most grateful to people like Richard and Don for their time, generosity and interest.

Barry J. Mishon,
Special Events Organiser

More Appeals
News—Page 21

WHAT COMES to mind when you think of music? Is it:

- Your favourite tune?
- Watching 'Top of the Pops'?
- Playing the piano?
- Going to the Proms?
- A particular singer?
- Revelling in the sounds of the organ at church?

Going to a disco?
It could be any, or all of these, or a profusion of other thoughts. Music has much to offer everyone and can give pleasure in many different ways.

Feeling of Independence

Most instruments can be played sitting down and therefore in a wheelchair. For instance—guitar, violin, woodwind, brass, recorder, some drums, glockenspiel, melodica, autoharp.

Often the playing of an instrument can help to keep fingers nimble, encourage hand/eye co-ordination and aid the identification of left and right. There are numerous instruments about and some can be made at home.¹⁾

Being Part of a Team

If physical activities are not possible, then music might help involvement with other people.

Most of us have some kind of singing voice but lack the confidence to use it. We think we are not good enough when really the voice is just rusty from lack of use! There are opportunities for singing or playing with others at folk clubs, choirs, amateur operatic societies, orchestras, bands, pop groups, etc., often run at adult education centres, churches, or by local music societies.²⁾ If they have not had a disabled member before, then explorations together, into the realism of joining, will be necessary.

Wheelchair Dancing can give much pleasure and there are thriving groups in various parts of the country with festivals at several regional centres each year.³⁾

Channelling Frustration

It is very easy for anger and resentment to build up inside if restricted movements limit activities. What a relief it can be to get rid of that frustration on a

Music—benefits by



drum, in handful of chords on the piano or, maybe, listening to loud music (on the headphones, hopefully) and moving whatever part is movable, to it. It is far more socially acceptable than throwing the crockery across the room!

Communicating

Listening to each other's favourite records can be an immensely enjoyable—and illuminating—pastime. Surprises can be experienced on all sides when unexpected tastes are discovered. Grandparents often have time to listen with their grandchildren and perhaps a mixture of Led Zeppelin and Beethoven's 5th symphony is possible. Staff and children at boarding school, sharing a five minute track of their best-liked records, can suddenly see quite a different side of each other.

Learning to play steel drums with a group of West Indians or being involved with Africans in drumming, can enable cultural barriers to be crossed painlessly.

Writing songs sometimes makes it possible to put into music thoughts too deep for utterance, thus expressing the inexpressible.

Stimulating the Mind

Countless songs can teach a great deal about life and lead to spirited discussion. For example:

- "Songs in the Key of Life" by Stevie Wonder. The booklet with the record really does encourage reading and, remember as you take in the words, that he is blind.
- "Do you love me?" from The Fiddler on the Roof, tells much of old Jewish traditions.
- Modern hymns (old ones too!) and protest songs express basic beliefs of many generations.
- Folk songs, shanties, negro spirituals, ballads and songs of the great masters all teach something of how people live(d) in other times or other places.
- Singing number songs⁴⁾ (*There were 10 in the bed*) and cumulative songs (*Green grow the rushes O*) are good for keeping mental faculties alert and it is exciting to discover how, imperceptibly, the concentration span can be extended by the imaginative use of music.

Recognising Sounds

Music games⁵⁾ and quizzes can be enjoyed by small or large

the score



The writer DAPHNE KENNARD runs the Music Advisory Service for Disabled People at the Disabled Living Foundation, 346 Kensington High Street, London, W14 8NS.

The service is available for disabled people of all kinds whatever their age or disability might be (physical, mental, sensory or emotional). As well as answering queries on all aspects of music, the aims are to keep in close touch with all other organisations concerned in music with disabled people, to be aware of new developments and to encourage people (professional workers, parents and disabled people themselves) by visiting, giving talks, stimulating training, disseminating information and in other ways.

Photo: Music workshop at the "From School to What?" conference (see p.5). Spastics Society photo.

numbers. Using a cassette player and television set at home it is easy to compile a TV Signature Tune Quiz to present to friends. How about making a cassette recording of sounds in the home, at school or wherever? Or perhaps 'sounds in the countryside' could be made on a day trip. What about using old records and seeing if listeners can put a name to the performers or piece and say what year it was?

Some children and young people with hydrocephalus can be extra sensitive to certain sounds or instruments (eg crackling paper, cymbals, church bells). The writer would be most interested to hear of any particular instances of extra-sensitivity of this kind.

Responding Rhythmically

Everyone has a heart beat, and the response of that pulse to the pulse of music is like a chemical reaction—and it is unique to each of us. Some click fingers in response, others tap a foot, while many just 'feel it' inside.

Mums might find it helpful to sing a song or have gentle background music when manipulating baby's joints; perhaps hanging bells or a chime ball will encourage a lethargic baby to stretch, to touch and so find the

sound; rhythmic background music can spur on children learning to walk with calipers; body awareness and finger control songs⁴⁾ can help with exercising and control; movement of fingers, wrists, arms, elbows, shoulders, neck, head, waist, seats etc are possible at any age—even in a wheelchair.

Losing Yourself

Most people have their own way of 'losing themselves' in music. It might be through classical, pop, musicals, jazz, folk, opera or any kind of music. It could be listening at home, attending concerts, performing in some way or perhaps writing music.

This opportunity for pleasure, whether we prefer it on our own, *with* others or doing it *for* others, is available for everyone. It takes some finding though, because the world of music is a complicated one to contend with. Musical contacts, books, instruments, sheet music, records, accessible concerts and evening classes, all need to be discovered. Don't give up! Keep on searching! It will be well worth it in the end for the pleasures of music will last you a lifetime.

ENDS

Following up some ideas mentioned in this article

- 1) a) Resource paper MP13 *Musical Instruments and Books About Making and Playing Them*. Available from DLF. Please send s.a.e.
b) Chapter on Instruments in "*Music to Help Disabled Children to Move*" by Daphne Kennard and Moyna Gilbertson. Published by the Association of Paediatric Chartered Physiotherapists and obtainable from Mr J. Harris, 25 Station Road, Menston, Nr Ilkley, West Yorkshire LS29 6JH. Price £1.
- 2) Resource paper MP4 *People and/or Organisations in an Area who Might be able to Help with Musical Contacts*. Available from DLF. s.a.e. please.
- 3) Wheelchair Dance Society. Details from Physical Education Adviser, The Spastics Society, 8 Starvecrow Close, Shipbourne Road, Tonbridge, Kent.
- 4) a) *This Little Puffin*. Nursery songs and rhymes compiled by Elizabeth Matterson, Puffin Book. 50p(?)
b) See chapter on Singing and Appendix A in book mentioned in 1b.
c) A list of song books suitable for nursery age children is being compiled and should be available from DIF in October.
- 5) Books of Musical games—*Pompaleerie Jig* by Diana Thompson and Kate Baxter. Published by E. J. Arnold. 35p. *Sounds Fun—a Book of Musical Games*. Schools Council Publication. 14p(?)



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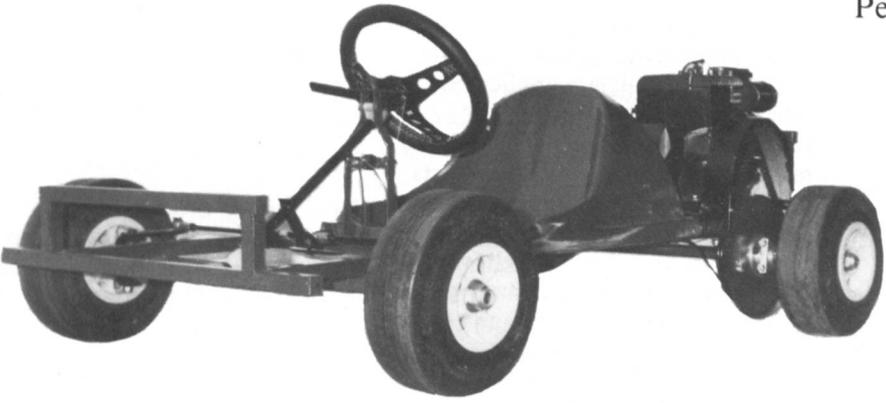
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SPINA BIFIDA PRODUCTS (CO-OP) LTD

Green Lane Industrial Estate

Pelaw, Tyne & Wear



Spina Bifida Products opens for business

SPINA BIFIDA Products (Co-op) Ltd, is an ambitious venture promoted by the North East Local Association, the basic aim being to provide training and employment for school leavers suffering from spina bifida and hydrocephalus, and other handicapped youngsters.

Parents in the Association have long been concerned about the difficulties involved in finding work for their children. That concern has grown in the current economic recession. Thus, after much deliberation, it was decided to create Spina Bifida Products, using grants from the local Association and local authorities.

An advance factory, rented from Tyne & Wear County Council, was occupied in late 1979, and because of the nature of the enterprise some degree of rent and rate relief was offered. With help from schools, colleges and private firms the factory has been fitted with necessary tools, benches and machinery.

An instructor and administrator are presently employed and it is hoped, by all concerned with Spina Bifida Products, that within the very near future the workforce will be increased. The firm's co-operative structure (based on ICOM model rules) will, eventually, enable the workforce to make decisions themselves.

At present the factory is making one product, but hopefully, in time, the product range will be increased to cover accessories and other leisure equipment, mainly suitable for the use of the disabled. The initial product upon which the factory has been based is the hand-controlled Tiger Fun Kart. For some years now karting has been a recreational activity within the North East Local Associations. Paraplegic children can begin karting by driving in a fun kart at 5-15 mph, and, if they wish progress to the more adventurous competitive driving. Karts have



been driven by handicapped children on gravel athletic tracks, school yards, tennis courts and disused aerodromes.

The Tiger Fun Kart is powered by a 3 hp, 126 cc. Briggs and Stratton engine. It has a deep adjustable seat and is suitable for all ages; both paraplegics and able-bodied. The price is £410 plus VAT.

Although the problems of obtaining industrial premises have been largely overcome, some important problems still remain. Making one product alone leads to problems of low and uneven turnover and thus, in order to be financially viable, a wide range of competitive products should be produced. Recently a prototype standing box has been made. Readers of LINK are invited to offer their ideas as to what other aids might be produced—perhaps a modification of something popularly used. If you have any thoughts on this matter then please write to the following address: Spina Bifida Products (Co-op) Ltd, Unit 2, Green Lane Industrial Estate, Pelaw, Tyne & Wear.

• Another co-operative is featured on p.17.

REVIEWS

The Open University Students' Association has issued a booklet entitled 'Access in Rome' containing information on access to museums, art galleries, archaeological sites and churches. The booklet is available from the OUSA Office, Sherwood House, Sherwood Drive, Bletchley, Milton Keynes MK3 6HN.

A Disjointed Life by Corbet Woodall.

Published by Heinemann, price £3.95.

In many ways, this is a declaration that the author feels able to return to public life, if not as full a public life as he enjoyed when he was a BBC newsreader.

What kept him out of things was the onset of the crippling and debilitating disease, rheumatoid arthritis. It may have drastically changed his life, but he still retains a sense of humour, humanity and perception which shine through this very readable book.

It is particularly useful for the non disabled in helping them to realise that people with physical handicaps are not a different species. Those who are disabled will find of particular interest the chapter about Corbet's involvement with the BBC series of programmes for the disabled, Contact. He was the presenter.

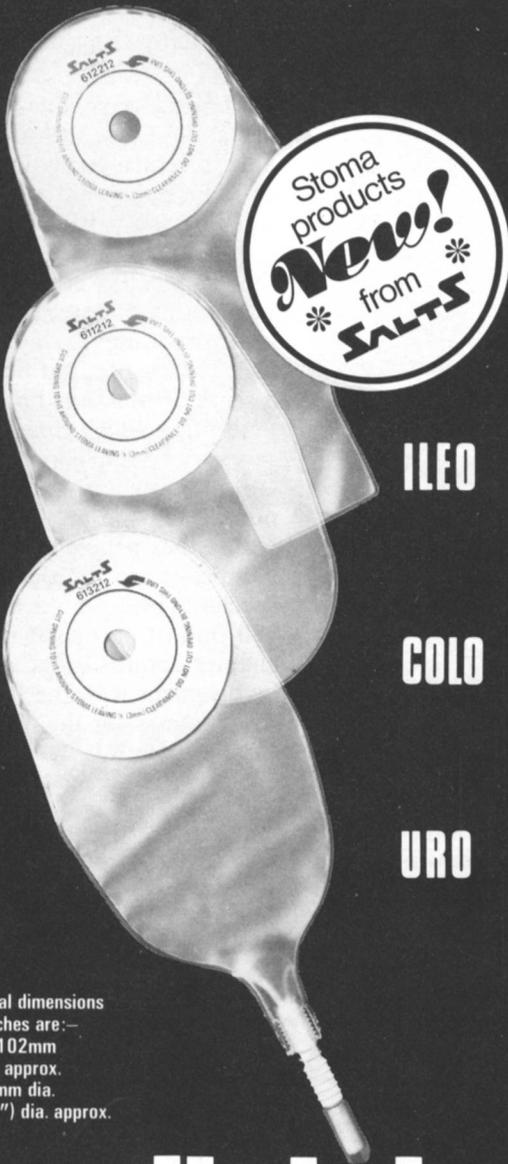
One of the Family by Dianne Hart and Jennifer Walters. Published by The Disabilities Study Unit, Wildhanger, Amberley, Arundel, West Sussex, BN18 9NR. (Tel: 079 881 406). Price 30p post free. Reduced prices for quantities.

This booklet has been published to help children and young people who have a sibling with a physical or mental handicap in the family. Running through it is the theme that such children are 'not handicapped children—just children with handicaps'.

Designed to fit readily into the pocket or school satchel it explains in simple terms how disabilities are caused and what it means to have a disabled brother or sister as 'one of the family'.

'Europe for the Handicapped Traveller', published by Mobility International, contains information on access, accommodation and other matters of importance to a disabled traveller. Altogether six issues will be published alphabetically exploring Europe, starting with Albania and finishing with Yugoslavia.

The brochures are available from Mobility International, 2 Colombo Street, London SE1 8DP.



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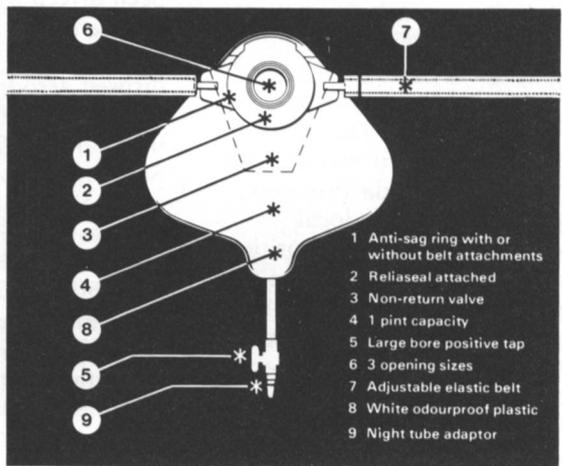
LW URINARY POUCHES

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

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

Cotton bag covers can be provided, and alternative adhesives are available for use with pouches without Reliaseal attached. 3 opening sizes available: 1", 1 1/4" and 1 1/2".

*** Now available in Small capacity size**



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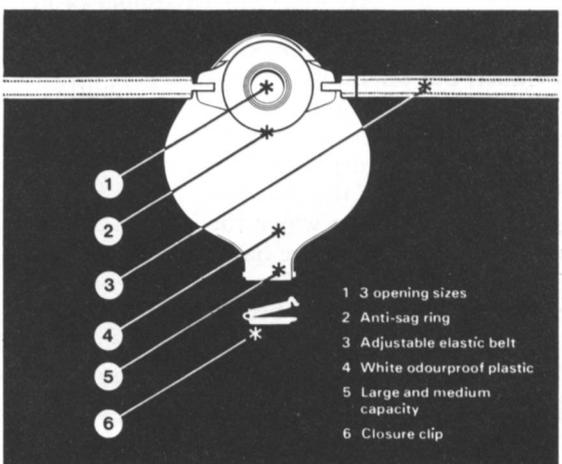
can be worn without any additional accessories, though some ostomists prefer the added feeling of security which LW accessories can provide.

LW is disposable, has bag covers, belts, closures, stabilising rings, is supplied in two capacity sizes, large and medium, odourproof, can be worn for a week without anyone knowing, and it looks as good as an appliance can look.

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

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

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GROW & SELL

Advice from THORNGROVE
The Spastics Society's Horticultural
and Agricultural Centre
at Gillingham, Dorset

by
Ted Rhodes, Land Management Adviser, Thorngrove

THORNGROVE is a Residential Centre for 28 handicapped adults specialising in the production of house plants.

From small beginnings and one small glass-house the Centre has developed until the present day when over 90 different kinds of house plants are produced commercially with a total production this year of 18,000 plants.

It was decided from the very beginning that for the handicapped to enjoy the full benefit from growing plants, they should also be involved in selling their product to the customer, consequently all plants are sold retail.

Gillingham being a small country town with a population of only 4,000, it was realised that to sell the quantity of plants we would ultimately produce, it was necessary to find some new method of marketing. It is difficult now to remember how the idea originated, but in 1970 the first sale of plants was held in factory premises.

This proved so successful that the idea was developed and expanded as production grew. Currently, there are 23 factories, office blocks,

universities, etc., which allow us to conduct sales on site. Each site is visited just twice a year, giving 46 sales spread throughout the year with a concentration at Christmas and spring-time. More than 8,000 plants were sold in this way last year.

Not only has this method proved successful in selling our product but these sales have promoted relationship and goodwill in many areas miles removed from the Centre.

For all organisations which have a surplus of products, not necessarily plants, we would recommend this as an avenue worth investigating.

To all those interested we offer the following advice:

- ★ Initial contact with a factory, office block etc., should always be at the highest level.
- ★ The ideal unit is one with 500 employees or more.
- ★ Location must be inside the factory at a site where the greatest number of employees will assemble usually in or near the Canteen.
- ★ Arrange the sale for pay-day (not always a Friday).
- ★ Do not visit a unit more than two or three times a year.
- ★ Advance publicity helps, i.e. posters displayed a week before sale day.
- ★ Select local factories, remember transport costs must come from profits.
- ★ Follow up the sale with a letter informing the staff on how successful the sale has been.

An insight into workers' cooperatives

'Workers' Cooperatives; a handbook' (1980) by Peter Cockerton et al is available, price £2.25 (plus 30p p&p), from Aberdeen People's Press Ltd, 163 King Street, Aberdeen, Scotland.

WITH MORE than 300 known workers' cooperatives trading in Britain, the cooperative movement can truly be said to be flourishing. This handbook on workers' cooperatives, published by the Aberdeen People's Press, is a revised, UK edition of a Scottish handbook which first appeared in May 1977.

It carries an outline of the history of industrial cooperation in Britain and the problems of establishing and running workers' cooperatives, covering such aspects as legal structure, internal organisation, management and finance. The final part considers the future role and importance of worker cooperation in the British economy.

There are five case studies of individual cooperatives, from a Scottish bicycle repair enterprise call Recycles to the well-known Mondragon organisation in the Basque region of Northern Spain.

The handbook concludes with a number of useful appendices, including a comprehensive list of resource agencies and addresses, examples of simple budgets, the Industrial Common Ownership Act (1976) and a selected bibliography on cooperation and cooperatives. The book is 'essential reading for any person or group thinking of forming a coop'.

Thorngrove is a large manor house set in 50 acres of grassland in North Dorset with residential accommodation for 28 adult spastics, both male and female. Purchased in 1965 to provide a centre for relatively lightly handicapped spastics who could benefit from an outdoor farming type of existence, it was at that time unique in concept. None of the residents is capable of achieving open employment.

From the very beginning, planting and development of the Centre has been based on the belief that the residents could achieve a large measure of independence and go far towards being self-supporting.

With all the many activities throughout the Centre no special provision (special tools, or equipment, etc.) has been made for handicapped workers. The aim is always to fit handicapped people into a normal working situation, grouping residents of dissimilar handicap together to achieve jointly what one able-bodied person could do on his or her own.

Reproduced from 'Growth Point' the magazine of the Society for Horticultural Therapy.



Baby Björn—about three months old. His mother is attempting to empty his bladder.

Bath-time for two-year-old Björn. Play develops his awareness of his body

At 2½ years Björn practices standing and stretching his hips following an operation.

This personal story from a Swedish mother was given as a paper to the Conference in Stockholm in October 1979, the Conference at which a decision was made to start the International Federation for Spina Bifida and Hydrocephalus. The Federation is to be inaugurated in Dublin in September next year.

THIS IS NOT a scientific report, it is not based upon a medical, psychological or sociological investigation. We shall only, by means of our experiences and knowledge, try to give an idea of how we look upon our task as parents of a child with spina bifida. At the same time we will focus on the efforts, which are required of the family, to manage the situation.

Immediately after birth the long haul to new-orientation and understanding of the complexity of the child's problem begins. The bitterness and mistrust parents may feel later is clearly related to their being left alone with their thoughts, worries and questions at this early stage.

The parents and their newborn baby start their life together under strained emotional conditions. There are many things the hospital personnel, including the doctors, can do to reduce the risk of disturbances between the parents and the baby. Here, in Sweden, the government has established

What's best for

routines for giving information to parents.

The child with spina bifida that the parents take home from hospital, often after a long time of worry and uncertainty, is not only a baby with all that that means, but also a little 'medical parcel' with red scars and a great need for nursing and care. Spina bifida is often looked upon as a number of specialist problems and, from a medical point of view, this is practical, but it proves to be very impractical and trying for the family.

NUMBERS INVOLVED

When counting the people who are involved in the regular care of our son Björn, we came to 23 people with different responsibilities. Some of these people work two to a team i.e. X-ray teams or a doctor and his nurse. If we now add the doctors, nurses of various kinds, laboratory assistants etc, who take care of Björn when he is in hospital we must count at least 10 people per ward. This means that the number of people amounts to at least 53.

Let us now look upon the resources available for psychological support and social help. There is hopefully one social consultant at each hospital clinic. She has to deal with the problems of all the patients in the clinic and

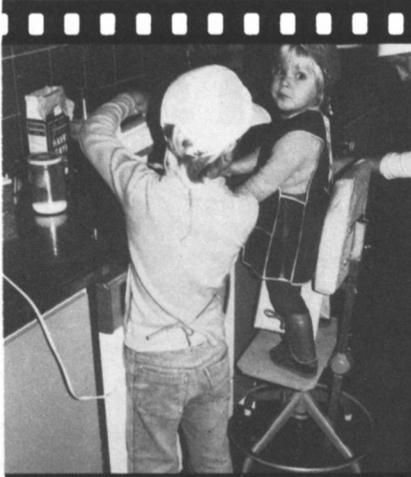
has neither time nor knowledge enough for families like ours. Each habilitation-clinic has one social consultant and can contact a psychologist if they don't have one.

In the Stockholm area, where we are comparatively well supplied, the social authorities have a special department for habilitation with two to three social consultants and a half or one psychologist per district. They serve about 300 families in each district and are responsible for supplying the necessary information to the communities in their district.

But there is no room for any regular checks on how the families are getting on, concerning the social side i.e. financial troubles or whether the parents, mostly the mothers, are tired out or have any other problems. So the physiotherapists often get the function of a social consultant as well, and this way the most acute problems can be attended to.

Unfortunately the families don't get anything like home-service and in many cases the social or psychological resources are introduced too late.

The three first years after our son's birth were dominated by operations, various close controls and X-rays at different hospitals and training, training and training. Since the treatment and training of Björn took most of the day we had



Björn, now 3 years, has the benefit of a home-made standing chair. Brother helps.



Four-year-old Björn and his best friend, Bomi the labrador dog.



Björn, just over four years old, sleeps with his toy lamb every night.

the Child?

to do the housework in the evenings and went to bed very late and very tired.

We literally lived with hospitals either staying there with Björn, or rushing to and from our house, taking care of the older children.

Sometimes we took the older children to the hospital. They were not too keen on it, just sitting in a corridor or a small room, waiting with mostly broken or incomplete toys or tattered books.

One of them, the boy, who was four and a half when Björn was born, became frightened of what he saw in the hospitals—odd machines, bandages and the other handicapped children.

Of course Daddy had to take a lot of time off from work to take part in all this. So he had to do part of his job at the weekends or in the evenings. We didn't see each other alone very often and when we did, there was so much concerning Björn to discuss. It would have been very helpful if somebody had come to deal with the necessary housework and looked after the children. As it was we only managed to get a lady from the social services a couple of afternoons or days now and then, and it took a lot of time and many phone calls to get it.

However time passed on and Björn's physio did a lot of good. Björn learned to crawl again fairly

well after a Shanced operation on one hip. He had a roll to help him crawl and bend his hips but he much preferred our labrador Bomi for this kind of training. We also introduced a programme for bladder training.

By and by we noticed that Björn cried when being lifted up and we could not see why. One day we were looking at photos from the other children's first years. They did a lot of things themselves when at the same age as Björn now was. They took part in their dressing and washing and expressed their will, very clearly, in various ways. And we remembered how their little legs often ran away in the wrong direction, when we were out walking.

BABY LIFE

We now realized that Björn lived a baby life at two and a half years of age. He was picked up and carried away when it suited his parents! Of course he cried when being interrupted in his playing and lifting up from behind.

We had been so busy training and amusing him, trying to give him a feeling of security, in spite of his handicap, never leaving him alone or leaving him one day too long in a hospital, that we had forgotten what children of his age normally do.

Since then we have been trying to integrate his training, especially his standing-training, with the normal activities of everyday-life. We also try to remember that Björn is a boy who grows older and older in spite of his crawling and wearing nappies (which is easier said than done).

As we said earlier, spina bifida is often considered a purely medical matter and the habilitation therefore is directed towards optimal future physical functions. But the social psychological, and educational difficulties which sometimes follow in the tracks of the physical training of these children is vital. It is here our job as parents come into the picture among all the experts. Some time there must be room for the child to develop as a human being and be able to play with other children.

What is best for the child? That is the question we must always ask ourselves and ask the people who are responsible for the habilitation.

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THE CHANCE to wine and dine in the company of celebrities and to listen to poetry and prose read by well-known actors and actresses is the prospect for 180 privileged people as LINK goes to press.

Special Events Organiser, Barry Mishon has organised a Gala Celebrity Poetry and Prose Reading Dinner in the Draper's Hall in the City of London for Tuesday October 7.

Those appearing are to include: Alan Howard, noted principal actor of the Royal Shakespeare Company and winner of the Best Actor Award each and every year since 1976; Judi Dench, one of England's principal actresses, also with the Royal Shakespeare Company; Diana Rigg and Gayle Hunnicutt, who will be reading something special and very different.

Individual tables are being hosted by equally eminent celebrities, including Lady Diana Cooper, Peter Egan, Rowan Atkinson, David Bailey, Sheridan Morley, Tom Adams, Tina Brown, and Victor Spinetti.

Tickets are priced at £25 per head, plus VAT and include all reception drinks, dinner, dinner wines, coffee, brandy/liqueurs. It's just possible one or two might be left. If anyone is interested they should contact Barry as soon as possible at the London office.

Feliks Topolski, internationally famed artist, has most generously donated, for the evening, a very limited number of individually signed sketches of some of the actors and actresses appearing. These will be for sale on the evening, but can also be reserved prior to the evening by anyone who may not be able to attend.

DURING the month of June we were fortunate in enlisting the help of Charles Shea Simonds who, in connection with his participation in a flying event sponsored by the Duke of Edinburgh entitled Dawn to Dusk, adopted ASBAH as a benefiting charity.

Hopping to it. . .



. . . Charles Shea Simonds with co-pilot Amanda Mitchell at the start of their marathon. They went on to take off from, and land at, no fewer than 32 airfields between 'dawn and dusk.' . . . Photo: Bradford Telegraph and Argus.

Mr Shea Simonds took off from and landed at no fewer than 32 airfields in Yorkshire and his report has now been submitted to the competition organisers where we all hope it will find sufficient favour to have him judged the winner.

Sponsorship was obtained on the basis of the number of take offs and landings completed and, under the organisation of Mr Michael Booth of the Leeds & Bradford Association, £4,000 was raised which, after the deduction of expenses, will be shared between the local association and Five Oaks.

IN YET another energetic vein, Mrs J. Peters organised sponsored 'sit-ups' for ASBAH. More than 30 ladies from her keep fit class contrived to raise more than £700 in the space of five minutes. If five minutes does not sound very long, one only has to try just a few 'sit-ups' in order to find out just how much these ladies put into this activity.

AT THE time of writing, August 30 is looming very large. It is the day set for the ASBAH Celebrity Boat Race on the River Thames.

The course for the race is between Chelsea and the Tower of London and participants will be James Hunt, Mick McManus,

Tom Adams, Gareth Hunt, Shaw Taylor, Terry Biddlecombe, Bob Spalding, Pippa Page, Linda Cunningham, Jenny Cresswell, Fiona Curzon, Jenny Lee-Wright, Judy Simpson and Caro Greenwood.

The boats being used for the race are six, 20 foot Shakespeares generously loaned by Peter Stuyvesant Cigarettes.

The cigarette company has most generously agreed to sponsor the event for the magnificent sum of £6,000 and I am sure that the occasion will be both memorable and enjoyable. By the time you read this we will at least know whether the sun does indeed shine on the righteous, as a wet day would certainly not work in our favour!

ALL THIS increased activity would be of little relevance were it not reflected by the balance sheet and I am sure everybody will be as relieved as I am to learn that for the past four months a small surplus has begun to emerge, taking into account legacies received.

This is, in no small measure, due to the fact that many Local Associations responded most generously to national office's cry for help. There is, however, a very long way to go before we may face the future with total confidence, but every effort is being made towards this end.

Judy Kay

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