Link

Association for Spina Bifida and Hydrocephalus/ASBAH 15p July/Aug 80

Cover Story: See Page 9

Campaign for higher Death Grant: IYDP News: Prof. Smithells' research gives cause for cautious optimism: The role of Action Research: Special Education: Sponsored initiatives

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

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Opinion

ONE OF the special features of the voluntary sector is the amount of energy and skill with which its activists pursue their causes. Whether they are concerned with the young or the old, with their own countrymen or with citizens of the third world, there will always be groups of dedicated men and women ready to respond to such needs with single-mindedness and devotion.

Indeed, it is this sense of purpose that has given the voluntary sector its strength. In their struggle to alter the established order of things, social pioneers throughout the ages encountered apathy, resentment and hostility, but succeeded in securing many of the great reforms which have transformed lives and led to services and institutions which we now take for granted.

In pursuing their causes they also had to compete with all the other legitimate claims for compassion being made by the great range of charitable enterprises which have come to characterise the British way of life.

However, from time to time challenges have arisen which draw many interest groups together temporarily in common cause, whilst allowing them to continue their every day work on a separate basis. There are many alliances of this nature at present. A number of them have been sparked off by cuts in the personal social services and by what are seen as challenges to the Welfare State itself. One such case concerns the death grant.

A joint campaign mounted in February 1979 has been gathering momentum in its attempt to increase the grant from its paltry out-of-date level of £30. The death grant was first introduced in 1949 and was meant to cover 60% of an average funeral. Evidence has reached DIDA (the Dignity in Death Alliance) that quite ordinary funerals may well cost anything between £250 and £400. To restore the grant to its 1949 value it would need to be raised to at least £153. With continuous inflation the precise amount is hard to calculate. It increases by a few pence each week.

The escalating costs of funerals lead to a dread among the elderly of what is still regarded as the final humiliation of a 'Pauper's burial' provided by the parish for those with no means. Even though it is now possible for local authorities to provide a funeral for those who died without means, the historic fear still hangs over the lives of old people who have been found to deny themselves quite simple comforts—perhaps even to have accelerated their deaths—in order to put aside money to cover a dignified burial.

Most of the organisations in the Dignity in Death Alliance are chiefly concerned with the elderly. But there are also those concerned with the sudden shock, both financial and emotional, that hits a young family on the death of a child. Here the grant may be as little as £9.00 to cover the cost of a funeral that may well be about £200. One of the leading campaigners in DIDA is ASBAH. Those of us working with the elderly have greatly welcomed ASBAH's contribution to the campaign where we are going around the country in order to get over a million signatures for a petition.

There are many other ways in which we should also be co-operating, and probably few organisations in the alliance believe this is the most important financial priority for the Government in relation to the many improvements we want to see in the quality of life for those we represent. However, we are united in believing that something must be done in the name of humanity to relieve the agonies of those of all ages who are experiencing unexpected or anticipated stress.

DAVID HOBMAN *Director of Age Concern England and Chairman of the Dignity in Death Alliance*

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

Elizabeth is Citizen of the Year

Twenty-one-year-old Elizabeth Shields has been named Citizen of the Year by the Sutton Coldfield Lions Club. They gave her the award for the work she did in starting the Sutton Branch of PHAB.

And, as the local newspaper, the Sutton Coldfield News reported, it meant a double celebration for the Shields family.

When Lions Club members arrived to tell her the news, the family were already having a party to celebrate Elizabeth's parents' silver wedding anniversary.

Elizabeth, who has spina bifida, did not know she was in the running for the title. She was selected from 29 other nominations.

The PHAB club was launched last year. Its aim is to bring together young adults—physically handicapped and able bodied—on a social basis.

The Sutton News quoted the Press Officer of the Lions as saying: "In spite of her disability Elizabeth is very resourceful and full of vitality and was instrumental in finding premises and getting together a number of young people from Sutton Coldfield and district."

With the title came a cheque for £100. This was to be donated to a charity selected by Elizabeth.

Earlier this year members of the Shropshire Local Association went shopping to equip their second holiday caravan. It's at Barnstaple in North Devon, and it took two years to raise the £9,000 needed to buy it. The other caravan is at Prestatyn in North Wales. Demand for holidays was so great that the second caravan became necessary. From left, back row: Stephen Richards, Mr Phillip Bowcock, Mr Terry Richards and Mrs Shirley Richards; front, Rachael Bowcock and Jamie Richards.

Now for a step in the right direction

THE ingenious adaptation on the left is the work of three-year-old Sarah Rabbett's father. Her mother, Mrs Barbara Rabbett of Berkshire in Herts, said it was quite simply a modified baby buggy.

The back wheels were removed and replaced by "rubber feet". A very heavy weight was then placed on the front bar.

This means that Sarah, who has spina bifida and is unable to walk, can pull herself up and stand. In May she actually managed her first steps, pushing the buggy.

PLEASURE

Mrs Rabbett said: "It's really given my daughter such a lot of pleasure and an incentive to walk. When we go out for short trips, I can hook the back feet of the toy buggy over the bar at the front of my Major buggy.

"The wheels at the front remain on the ground and Sarah leans forward a little and can push her dolly along in front of us. It's given her so much fun."

Readers of the Star Newspaper (Aldershot) have rallied in response to an appeal in the newspaper and provided enough money to buy five Thistle Trikes. The Trikes were handed to the North Hants, West Surrey and South Berks Local Association at a special reception in March.

Hoists—and how to take strain out of lifting

Hoists and their use by Christine Tarling, MBAOT. Disabled Living Foundation, 346 Kensington High St, London W14 8NS. Price £8 including p and p.

ASBAH helped in the preparation of this informative 318-page book about hoists and is pleased that it is now available.

It is intended to be a textbook for those caring for disabled people, particularly for those in long stay hospitals or homes, as well as for architects, administrators, supplies officers and others who have to prescribe hoists. However, anyone who has a severely disabled person in their family should find it useful.

There are descriptions, reports, clear line drawings of different types of hoists. The author also explains how the heavy job of lifting can best be done so that families, nurses and others will be able to use hoists without fear of suffering back damage.

Programme moves to new time

Does He Take Sugar, the BBC Radio 4 programme of special interest to disabled listeners, has changed to a new transmission time of 7 pm on Sunday evenings.

The programme also has its own Correspondence Bureau, so if you would like a pen pal get in touch. The address is: Marlene Pease, Editor, "Does He Take Sugar?", Room 7054, Broadcasting House, BBC, London W1A 4WW.

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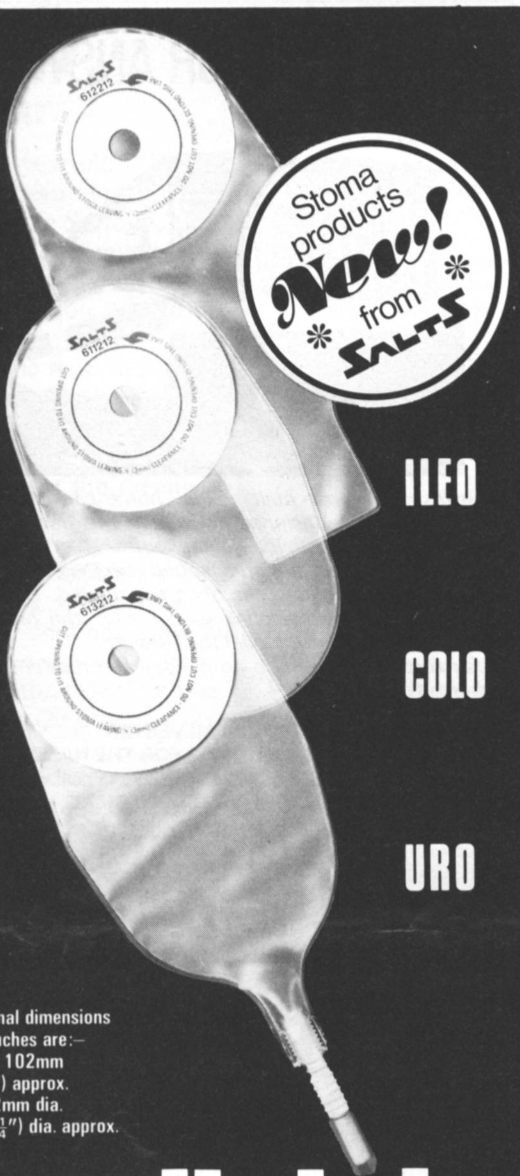

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paediatric

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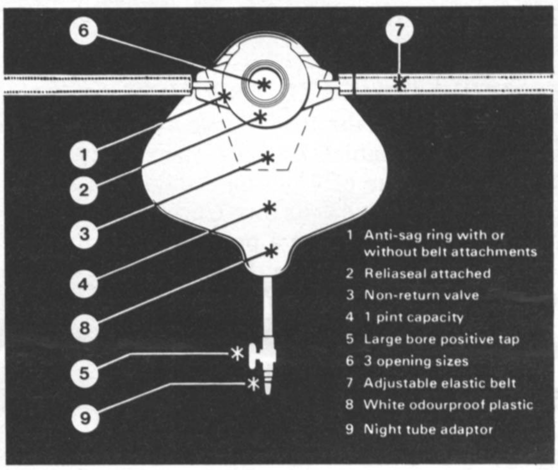

1 Anti-sag ring with or without belt attachments
2 Reliaseal attached
3 Non-return valve
4 1 pint capacity
5 Large bore positive tap
6 3 opening sizes
7 Adjustable elastic belt
8 White odourproof plastic
9 Night tube adaptor

LIGHT WHITE ILEOSTOMY POUCHES

can be worn without any additional accessories, though some ostomists prefer the added feeling of security which LW accessories can provide.
LW is disposable, has bag covers, belts, closures, stabilising rings, is supplied in two capacity sizes, large and medium, odourproof, can be worn for a week without anyone knowing, and it looks as good as an appliance can look.
Any ostomy adhesive and sealing washers are suitable. None can harm the tough, soft plastic.
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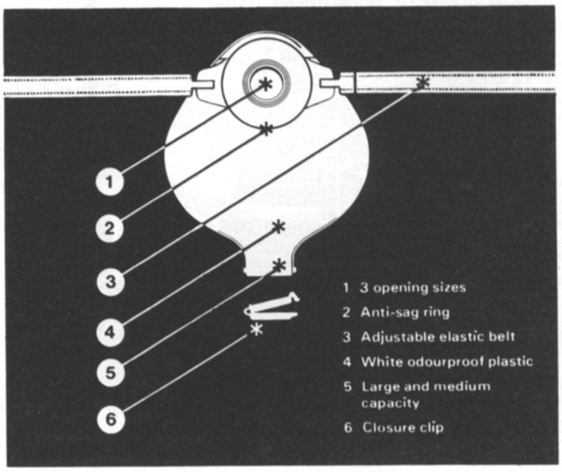


1 3 opening sizes
2 Anti-sag ring
3 Adjustable elastic belt
4 White odourproof plastic
5 Large and medium capacity
6 Closure clip

Where government stands on Warnock

THE GOVERNMENT has accepted the Warnock Committee's recommendation that the existing statutory categories of handicap for assessing special educational needs should be replaced by a new framework based on the needs of individual children. Mr. Mark Carlisle, Secretary of State for Education and Science, has said legislation will be introduced early to establish the new framework.

In a statement to the House of Commons, he said the new framework would be substantially on lines recommended in the Report. The new legislation would also incorporate provisions designed to safeguard the interests of children with severe or complex special educational needs, including arrangements for more widely based assessment and for the recording of individual needs.

Parents would have the right to adequate information and consultation about the education offered for their children written into the legislation.

LOCAL

Mr. Carlisle added: "Many of the other recommendations in the Warnock Report were not addressed directly to the Government, but to those concerned with the local provision of education, health and welfare services.

"Some recommendations, for example those relating to nursery education, teacher training and further and higher education, have major implications for central and local government expenditure and their implementation must be considered in the light of the economic situation and the need for restraint which it entails.

"The Government's current expenditure plans provide for the maintenance of expenditure on special education at its present level despite the fall in the size of the relevant age groups.

"We propose to lay before Parliament in due course a White Paper outlining the form the new legislation might take and dealing with other recommendations made by the Warnock Committee."

The Act Now demonstrations
Photo: Margaret Murray

Marchers defend the Act

BECAUSE of government economic cuts, many local authorities are not providing disabled people with the assistance due to them under the 1970 Chronically Sick and Disabled Persons Act.

The Act Now campaign held a demonstration and lobby in London on June 11. Led by Mr. Jack Ashley MP, Chairman of the All-Party Committee on Disability, they marched to the offices of the DHSS where they handed in letters of support received from a large number of voluntary organisations.

It had been hoped that Mr Reg Prentice, Minister for the Disabled would meet the marchers, but he declined.

This was followed by a rally where marchers heard Mr. Ashley, Mr. Alf Morris, the originator of the Act, and Mr. Bert Massie from RADAR, who is himself disabled, call on the government to fulfil their obligations to disabled people.

The marchers then went on to the House of Commons to lobby their MPs.

New standards for sheltered housing

THE COST of providing a lift in two storey blocks of sheltered housing will, in future, be admissable for subsidy. Until now, local authorities could not obtain any subsidy unless the block was of three or more storeys. This follows an announcement at the beginning of the year that the space standards for one person sheltered flats were to be increased to enable Councils to build them with a separate bedroom rather than a bed recess.

Narrowboat launch

THE Chairman of the Spinal Injuries Association Baroness Masham has launched the first narrowboat in the world which can be skippered from a wheelchair.

The six-berth canal boat, "Kingfisher", fitted with two Hymo hydraulic lifts and specially designed to cope with the needs of people in wheelchairs was the idea of Paul Bush, National Treasurer of the Association who was injured four years ago in an accident on his farm near Daventry, Northants.

Disabled students in halls of residence

THE National Union of Students has produced a list of Universities and Polytechnics which have at least one room in a hall of residence which has been designed or adapted for students with locomotor disabilities. The list also gives details of rooms which are not specially adapted but which have been used by disabled students. The list is available from the National Union of Students, 3 Endsleigh Street, London WC1H 0DU.

RADAR enquiry

RADAR would like to hear of any examples of housing which has been privately built for sale and has been designed to include the essential 'mobility housing' criteria: level access, doors that are wide enough to allow the passage of wheel chairs (i.e. 900 mm doorsets) and a bathroom and WC at entrance level. RADAR are not, in this enquiry, concerned with housing that has been specifically built for a known disabled person or housing that has been adapted.

Sharon's a gold medallist

Fourteen-year-old Sharon Munton of Almond Road Kettering has set a new national swimming record. Sharon knocked 1.4 seconds off the record for the 25 metres breaststroke at the annual national swimming gala for the disabled, bringing it down to 31.4 seconds.

The gala was held at Stoke Mandeville and Sharon and fellow pupil, Allan Robinson of Kingsley School, Kettering were selected to represent the Cambridgeshire region. Both teenagers walk with the aid of sticks.

Sharon, a member of Northants local association will shortly be sent a gold medal by the British Sports Association for the Disabled.

Employment

THE Disablement Income Group Charitable Trust has a £26,000 grant from the Leverhulme Trust to research ways of improving employment prospects for the disabled.

Growth point

Quarterly magazine of the Society for Horticultural Therapy and Rural Training Ltd, 51 Catherine Street, Frome, Somerset BA11 1DA.

Anyone interested in horticulture, agriculture or gardening for people with all kinds of disability will find this magazine useful. The Society was formed two years ago, funded by the Rowntree Trust, to introduce, promote and improve schemes of horticultural therapy or rural training. Associate membership, which includes Growth Point, is £6 a year.

Guide to London

THE London Tourist Board hopes next year to publish a guide to London for disabled people. It would be grateful for any information, based on personal experience, about buildings and tourist sights in London that can be enjoyed by disabled people. Contact Ilva French, London Tourist Board, 26 Grosvenor Gardens, London SW1W 0DU.

Water sports in Wales

THE RANCH Adventure Centre in Snowdonia National Park—at Llanbedr on the North Wales Cambrian coast—has become a very popular adventure centre for young people. All kinds of outdoor pursuits are possible from the centre, many of them suitable for the disabled.

Now comes the announcement of the opening of a brand new water sports complex and residential centre nearby, at the mouth of the River Artro at Pensarn Quay. Whilst available for all youth groups the new centre will specialise in provision for the young handicapped. The main social area and all the bedroom accommodation is on the ground floor, and the buildings have been adapted for the disabled with ramps, large toilet cubicles etc.

For more details write to: the Manager, The Ranch Administration, Llanbedr, Gwynedd, LL45 2HU. Tel: Llanbedr 358.

Cover Story

A FAMILY in tune. Two-year-old Susan Gray and her four-year-old brother Paul. Their mother, Dr. Jennifer Gray adds some words to the music:

"Susan is a joy and a blessing. What her existence has done is to open our eyes to a problem which most normal people, I suspect, would prefer to ignore. It has made all my patients sit up and think.

"The Association, and in particular our local social worker, has been a godsend, and just at the time when we felt most confused and let down by everyone (when Susan was about six weeks old) she came to the rescue."

LINK's front cover features Susan and a special friend—*her dolly!*

International Year of Disabled People

AS YOU already know, 1981 is the International Year of Disabled People. The United Nations has laid down five aims for the year, and in order to try to achieve some of these, voluntary organisations in the U.K. have set up groups to look at projects closely related to these aims.

Below we list the aims and the headings under which the various groups will be carrying out their work.

Aim—to help disabled persons in their physical and psychological adjustment to society.
Groups: Attitudes, Family and Disability, Relationships.

Aim—to promote all national and international efforts to provide disabled persons with proper assistance, training, care and guidance, to make available opportunities for suitable work to ensure their full integration into society.

Groups: Employment, Technology Development, Housing

Aim—to encourage study and research projects designed to facilitate the practical participation of disabled persons in daily life, for example by improving their access to public buildings and transportation systems.

Groups: Access, Mobility

Aim—to educate and inform the public of the rights of disabled persons to participate in and contribute to various aspects of economic, social and political life.

Groups: National School Projects, Information.

Aim—to promote effective measures for the prevention of disability and for the rehabilitation of disabled persons.

Groups: Prevention

Each of these groups are looking at several projects and will then decide which ones to submit to the Executive Committee of IYDP for approval. It is hoped that projects begun in 1981 will continue and be of benefit to disabled people long after the year is over.

ASBAH is represented on all of these groups and we will keep you informed of any further plans which are made. In the meantime, if you have any ideas for a project which you think may be appropriate to celebrate the year then please send them to us and we will see that they are passed on to the relevant group.

We would also be very interested to hear of any plans your Association has for celebrating IYDP.

Beverley Holland

• The BBC's Continuing Education Department hopes to produce some 20–25 new programmes linked to IYDP in 1981, and repeat another 30 relevant programmes. In addition there will be a major 50 minute documentary for transmission at peak viewing time to herald IYDP.

• Local Councils for Voluntary Service (in some areas called Guilds or Councils of Voluntary/Community Service) have been asked to co-operate with local Associations for Disabled to arrange meetings and bring together all those who may be interested in IYDP and plan activities.

Why there can be cautious optimism on the prevention of spina bifida . . .

R. W. SMITHELLS
Department of Paediatrics & Child Health
University of Leeds

TEN YEARS ago, a grant from Action Research enabled my department to embark on a programme of research into the nutrition of women in early pregnancy to see if there might be any connection between vitamin deficiency and congenital malformations of the brain and the spinal cord (anencephaly and spina bifida). The first seven years' work provided circumstantial evidence in support of the idea.

We therefore proceeded to test the hypothesis by giving extra vitamins to mothers prior to conception and through early pregnancy. In order to reach a conclusion as quickly as possible, we decided to try this idea out on women who had already had at least one affected baby, and who therefore faced about a 5% (1 in 20) chance of experiencing the same misfortune again.

We were also able to enlist the help of researchers in other centres who were interested in the same problem, so that the study was eventually being carried on simultaneously in Leeds, London (Guy's Hospital), Manchester, Chester and Belfast.

Towards the end of 1979 the preliminary results looked sufficiently encouraging to deserve publication, and a short report appeared in the Lancet on 16 February, 1980. Briefly, we were able to report on 178 infants born to mothers who had taken vitamin supplements. Some of the babies had been born; others were unborn but the mothers had had an amniocentesis test.

In the normal course of events we would have expected about nine of these infants to be affected. In fact, only one was. In Northern Ireland, which has one of the highest natural rates of anencephaly and spina bifida in the world, not a single supplemented mother had an affected baby.

Mothers in the same centres over the same period who had *not* received vitamin supplements experienced the expected recurrence rate—12 out of 240 babies.

Does this not mean that we have discovered how to reduce the incidence of these defects, if not totally prevent them? There are several reasons for being very cautious about interpreting these preliminary results.

First, there have already been several promising ideas about the prevention of spina bifida none of which, so far, has stood up to critical testing.

Second, the difference between the one case observed and the nine expected just *could* be a fluke. Statistically, there is less than a 1 in 100 chance of it being so, but it is possible.

Third, and most important, the mothers given the vitamin supplements are not necessarily representative of *all* mothers who have had an affected baby and we may have unwittingly treated a group of mothers who had a much smaller than average chance of having another affected baby. (If this proves to be the case, it will be an important piece of information in its own right because current genetic counselling practice is based on the belief that all couples who have had an affected child face similar risks of recurrence.)

Our original research plan, which was scientifically sound, had to be abandoned because of ethical considerations. The study we did was more ethical but less scientific.

It is probably fair to say that this approach to preventing spina bifida has got further than did any of the earlier ideas, but more work needs to be done, not only by us (who might be suspected of having a vested interest in proving ourselves right!) but by others as well. Meanwhile, guarded optimism may be the appropriate attitude to adopt.

Research means starting with one question and ended up with ten. We are only just gathering information about *other* birth

A child at Oaklands special school, near Salford, wears an appliance devised and developed with the help of a grant from Action Research. It is known as the Salford Swivelwalker and is particularly valuable for spina bifida youngsters.

defects in these babies. Much larger numbers will be needed before we can tell whether such congenital malformations as congenital heart disease, hare lip and cleft palate are affected by vitamin supplementation.

We do not know whether treatment *before* conception is essential. If it is, how could we deliver it to everybody who might benefit from it? I—and others—have long predicted that traditional antenatal care must one day give place to preconception clinics. If the vitamin work stands up to further study—and that must be the top priority—the need for change becomes more pressing.

In conclusion, I should like to thank Action Research for backing an outsider 10 years ago. It is going well with one fence to jump, but the winning post is still a little way off.

- **Prof. Smithells has received a further grant of more than £33,000, from Action Research, to enable him to continue his research.**

. . and why Action Research plays a vital role

ANDREW BREARLEY-SMITH
Director, Action Research

A LONG time ago (longer than I care to recall) I was asked to write an article for LINK by way of introducing members of ASBAH to the work of 'Action Research'—The National Fund for Research into Crippling Diseases—particularly the Fund's support of research into spina bifida. I am delighted to be able to say that one of our earliest grants for research into spina bifida has begun to show some positive results, and as this is reported on this page, there can be no more appropriate time to acquaint you with our work.

Action Research has long maintained a close interest in your research needs, knowing that the heavy demands upon ASBAH resources in providing advisory, welfare and residential care services for those with spina bifida and hydrocephalus and their families leave little room at the end of the day for research purposes.

THE BEGINNING

The initiative to launch a charity concerned with human problems usually derives from impatience, frustration and a recognition, on the part of an individual or a small group of like-minded people, that swift and effective action is more likely to be obtained from the energetic, enthusiastic and direct involvement of the public, rather than leaving it to the State. Such was the case with Action Research, founded in 1952 to raise money for medical research into the cause, prevention, cure and treatment of poliomyelitis.

When a means of preventing polio had been found and proved effective, the National Fund for Poliomyelitis Research as we were then called, did not cease to exist but widened its area of interest to include all crippling diseases and eventually adopted a change of title in keeping with the change—The National Fund for Research into Crippling Diseases.

But the story is still not complete. 'Action Research' now supports medical research into all aspects of crippling, regardless of cause, and can therefore respond to need, unfettered by consideration of disease, condition or age group. There is nevertheless an emphasis within our broad remit upon the prevention of disability, especially in the child, and our current support of some 200 research projects reflects this emphasis.

Not surprisingly this has led to considerable support of research into spina bifida.

Three of the twelve grants awarded this latest quarter year are for research into neural tube defects, and I hope we may be able to maintain the extent of our support but financial considerations are not the purpose of my article; you will be more concerned to see the following list of projects currently funded by Action Research:

Department of Genetics and Biometry, Galton Laboratory, University College London: Dr. W. H. James. £22,830. To investigate the hypothesis that female twins, identical twins and cases of spina bifida and anencephaly have a common cause—that of reproductive delay.

Department of Development Biology, Marischal College, Aberdeen University: Dr. J. McKenzie. £13,663. To do experimental work designed to verify the hypothesis that spina bifida and associated anomalies are caused by luteal phase insufficiency.

Department of Anatomy, University of Cambridge: Dr. M. H. Kaufman. £16,805. A three year investigation into some of the environmental, genetic and intracellular factors which may be involved in the development of spina bifida.

Department of Child Health, Welsh National School of Medicine: Professor K. M. Laurence. £12,500. To continue a study of the medical, psychological, social and educational consequences upon the family following the birth of a child with spina bifida.

Paediatric Research Unit, Guy's Hospital Medical School: Dr. M. J. Seller. £26,324. Basic research into the cause of anencephaly and spina bifida. The cause is unknown but there seem to be several factors involved and both genetic factors and the environment are implicated.

Radcliffe Infirmary, Oxford: Dr. N. J. Wald and Professor A. C. Turnbull £18,844. For a two year collaborative multi-centre study in relation to the antenatal diagnosis of neural tube defects.

Department of Human Genetics, Western General Hospital, Edinburgh Dr. D. J. H. Brock. £27,610. Over 2 years for the

Continued on page 12

The story of one mother shows value of amniocentesis

IN THE case of this mother the baby happily proved perfect, but she did point out that had the test proved positive—meaning that the foetus was abnormal—she would have chosen to have the pregnancy terminated.

EARLY IN 1978 I found that I was expecting my third child. That may not sound very unusual to you but for me it was very frightening as I have a daughter, Andrea, who was born with spina bifida and hydrocephalus. Andrea is now nine but still cannot walk without the aid of calipers and crutches.

I went to see my doctor and asked if I could have a test to see if the baby I was having was going to be the same as Andrea; you see, the chance of me having another child with spina bifida is 1 in 4.

I went to the local maternity hospital to have the test done when I was 16 weeks pregnant. The name of the test is amniocentesis. What they do is to give you an ultrasound scan to see how big the baby is and to make sure it is not twins. Then they insert a needle into the lower part of the abdomen and take a small sample of the fluid which surrounds the baby, to be analysed for any sign of a protein known as A.F.P., which is produced by a developing baby, and if the baby has spina bifida, this protein will have leaked from the opening in the back and gone into the amniotic fluid.

When I went for the scan I was very worried as I had never had anything like it before. But I had no need to worry as it was very nice. I saw and heard the baby.

What they do is, lay you on a bed and put olive oil on your stomach. Then a doctor puts a machine onto your stomach and moves it backward and forward and it picks up the shape of the baby and puts it onto a T.V. screen so you can see the baby. The doctor moves it up and down the spine and over the head to make sure that there are no abnormalities anywhere. You can also hear the baby's heartbeat. It is a very nice feeling seeing and hearing your baby so early on.

I then had the amniocentesis at the maternity hospital. I was taken into a room where a doctor gave me injections in my stomach to freeze it. Then he inserted a needle through the skin and into the womb; this is a simple process and does not hurt at all. They then take a sample of the fluid and send it away for analysis.

I had to wait about three weeks for the results. It was the longest three weeks in my life, not knowing if they would say "sorry, things aren't right" or "everything is O.K." Finally, I went to see the doctor and he said everything was O.K. and the baby was going to be born alright. It was the best news I had heard.

When the time came for the baby to be born I was very frightened. It was seven in the morning and my husband had just gone to work when I started with a stomach ache. I lay in bed and though, it will go off, as I had forgotten what labour pains were like. I waited until about 10 o'clock before sending for my husband. When he came home I said I would wait a bit longer before phoning the hospital. At about 1 o'clock he phoned the hospital and said that I was having the contractions every ten minutes. I had to go in right away.

When I reached the hospital I was taken to a room where a nurse took all particulars and got me ready for the delivery. When you are ready they take you into the labour room, where they put you onto a machine that monitors the baby's heartbeat and your contractions. It is to make sure that the baby is not fretting. At three o'clock visiting, my husband came to see me and was able to stay with me until baby was born.

All through labour I was hesitant to bear down when told to do so, because I was so afraid that there would be something wrong with the baby, even though I had been told she was perfectly alright. Eventually, with reassurance from the nurses and my husband, I gave birth to an 8lb 8oz baby girl. My first reaction was to say, "her back, is it O.K.?"

They held my baby up to show me, cleaned her down and gave her to me in my arms. She was lovely and well worth all the trouble and anxiety I went through.

Action Research–continued from p.11

assessment of the potential value of maternal serum acetylcholinesterase measurement in the early antenatal diagnosis of foetal neural tube defects.
Department of Paediatrics and Child Health, University of Leeds: Professor R. W. Smithells. £33,111. Over three years in connection with the possible prevention of neural tube defects by periconceptional vitamin supplementation (following the work reported in this issue by Professor Smithells).

You may conclude from this list that our support is usually limited to basic and clinical research extending on occasion to social and environmental aspects. In practice about 20% of our work, under the general heading of 'Medical Engineering' involves the research and development of apparatus and techniques designed to aid diagnosis or alleviate physical handicap, including aids to daily living, orthoses and prostheses.

Such projects are too numerous to mention in any detail, but many are relevant to the possible consequences of spina bifida, be they to do with the (Salford) swivel walker, for example, prenatal diagnosis, or surgical techniques.

I hope to have impressed you with the extent of our support of research in your area of need. More so, I hope and pray that the fruits of our work may rid future generations of spina bifida and hydrocephalus by means of primary prevention, and bring new hope and comfort to those with existing handicap.

AS THE cold wind of financial cutbacks blows through the country's educational system, one sector faces a peculiar dilemma. Special Education—based on the findings of the Warnock Report—now has the factual basis for a great step forward. But, at what should be a moment of great optimism, the financial wherewithal is missing. Having established the merits of their case, campaigners now have to go on to secure the backing necessary for further progress. It was against this background that, Mr Stanley Segal, Principal of the Ravenswood Village for the Mentally handicapped, and formerly headmaster of the Franklin Delano Roosevelt School, spoke in April to the annual conference of the National Council for Special Education of which he is President. Here LINK publishes an edited version of that talk.

Special Education: Facts and Finance

THE OMENS are disturbing and the tasks which face us are escalating. Yet, when in the history of social education have the means for improving the quality of life for handicapped individuals been so promising, so varied, or so widely available?

Before the Budget, the NCSE Executive responded to expressions of concern from various colleagues within the field of special education by circularising all its branches in an effort to obtain hard facts. The evidence is unquestionably sufficient to sound an alert.

For example, in an authority which has carefully protected existing provision for the handicapped, an experienced Adviser in Special Education expressed concern at the impact of surrounding attitudes. During a telephone conversation, he went on to say that the voice of special education in certain local corridors of power was being muted. In one case by the simple expedient of not appointing an officer to replace a key figure who has retired. In other cases leading personnel are said to be withdrawing behind their dykes, he says, cowering, to await the blows.

The day after this conversation a Divisional Director of Social Services speaking at a regional conference of the British Institute for Mental Handicap, commented that whilst Social Services are increasingly looking to the special needs of the severely handicapped by generally extending the range of provision available "and more specifically by encouraging a more enlightened approach to day services", public expenditure cuts have meant that many projects and improvements are having to be shelved. He urged special schools to appreciate fully the implications for them and prepare pupils as much as possible for the less protected environment they will experience in the adult world.

Almost immediately after this conference, in a letter from an active branch which is sited within one of the more backward of local authorities, the latter is described as being intent upon cutting £100,000 from the special education budget in 1980/1 and more the year after.

'UNSEEN' CUTS

The branch warns that in addition to the effects from direct cuts, the quality of remedial education in its ordinary schools is threatened by the effects of 'unseen' cuts. There is some evidence that this authority which has no remedial education adviser, is proposing to close its Remedial Teachers Centre, and make an unspecified cut in its School Psychological Service.

Other teachers centres which have provided in-service training for remedial teachers are also about to be axed. Dangerous obstacles are appearing too in the way of provision for handicapped children in the 16–19 age range. Contrary to certain expectations this is affecting the voluntary sector and the relationship between the statutory and the voluntary sectors. A colleague from the National Children's Homes, for example, observes that whereas the ILEA continues to be extremely co-operative another LEA, which had formerly been co-operative, was now cautioning him that all future recommendations for post-sixteen education would be gone through with considerable care.

The development which is currently being accentuated in our more retarded local authorities goes counter to all that was intended in the 1944 Butler Education Act and counter to all that has been achieved by successive governments since the end of the war.

Is it in line with the intentions and declared policy of the present Secretary of State for Education, Mr Mark Carlisle, who despite the fact that he could promise no major assistance towards an improvement in provision has stressed that he sought to keep spending on special education at its present levels notwithstanding the fall in school rolls. Is it in keeping with the law which ensures the right of *every* young man to continued education from the age of 16 to 19?

The situation is complex, uneven and worrying. But no-one who knows the history of special provision, no-one who works in a special school or class, is likely to be thrown off-course by a mere economic blizzard, however severe it may be.

Those in the 1960s who confidently advanced the slogan that "No Child is Ineducable" must now consider whether they believe that "Every Politician is Ineducable". This does not mean that they may not exhibit severe

Continued from Page 12

learning disabilities. Successive governments have proved to suffer from very serious learning handicaps indeed when it came to grasping the central issue in our field—that we must not only recruit an adequate force of relevant staff with appropriate attitudes, but must provide them with special and ongoing training.

The need for special training, said Mr Segal, was one of the key recommendations in the Warnock Report on Special Educational Needs. Two others concerned pre school provision and post school provision for the 16–19 age range. In a statement to the House of Commons, Mr Carlisle had accepted the need to shift from the present system of assessing special educational needs by defined categories of handicap to one based on the needs of individual children. But the prospect for progress in the key areas was not very good.

As for the proposals for nursery education, for teacher-training and further and higher education, Mr Carlisle, said that their implementation must be considered in the light of the economic situation and the needs for restraint.

After Mr Carlisle's statement, Professor Mittler (a dedicated pathfinder on behalf of the mentally handicapped) and I were given an opportunity to put our views with regard to priorities and to stress to both Mr Carlisle and to his advisers, our concern with regard to teacher-training. We had a sympathetic hearing, but echoing with confounding effect in everyone's ears, including those of the Secretary of State, was the question of expenditure and constraints.

We knew that despite the statement by Mr Carlisle that the Government's expenditure plans provide for "the maintenance of expenditure on Special Education at its present level despite the fall in the size of the relevant age groups", local authorities would determine their own priorities.

THE Spastics Society's school, Meldreth Manor, near Royston, Herts, caters for cerebral palsied children from 5-16 who are severely intellectually retarded. The aim is to give each pupil a great degree of independence as possible in a home-like setting.

We stressed that a key appointment in each LEA could achieve a great deal; for example, a curriculum officer for Special Education attached to a teachers' centre or a Special Education resource centre. Such an appointment might mobilise local interest in the development of in-service training and curriculum development and achieve a great deal at very low expenditure. Even if the government was not able to increase the amount of money devoted to special education the DES could at least make suggestions for ways in which the best use could be made of scarce resources.

We expressed concern about the needs of pre-school children. The valuable research which Professor Chazan had carried out together with Dr Laing, and which helped the Warnock Committee in its deliberations, indicates the many things which flexible staff are achieving in their efforts to integrate one or two severely handicapped infants into a main-stream group.

Physically handicapped infants who were not suffering from mental retardation or behaviour disorders were the most readily accepted and acceptable. Children with mild handicaps could be accepted if staff were given a little extra help and there was some evidence that where ancillary help was available it was not always being used to best advantage. Lots of equipment which was available was not known to relevant staff.

Not only was this an important starting-line for integrational developments, but early action to assist handicapped children could now prevent a great deal of later difficulties. But we now faced a new obstacle. Whereas expansions of nursery education in general could absorb a proportion of the handicapped within normal provision, that expansion was now halted, a shrinkage threatened. *If we now relied on normal provision we would be depriving handicapped infants of opportunities to get any form of early special provision. And even where we did place handicapped infants into normal provision we came again to the need for appropriate training of staff.*

As for the over 16s we pressed strongly for Government guidance on this. Promising developments have been taking place in Colleges of Further Education. But mentally handicapped young people for example, do not automatically find appropriately trained staff there. There is inevitably, confusion about what and how to teach.

The law is not threatened by juvenile delinquents only. *We found it necessary to comment that those local authorities which are forcing young people from special schools to leave at sixteen without any provision for education from the age of 16 to 19 are breaking the law.*

Mr Segal then detailed the surge in progress, leading up to the 1980s.

So we come to the present decade, the 1980s. And *we begin with the acceptance by the Secretary of State for Education and Science of the Warnock Report.* Percolating upwards towards local and national government, are the national findings that special education needs are not restricted to the 1% or 2% now in special schools or special classes: 16 to 20% of the pupils are officially recognised to have special educational needs.

Biomedical research gives more

substantial evidence of the promise of the eighties, which could see the eradication of certain handicaps.

We above all, must recognise that a multiplicity of creative forces are at work in the area of prevention as in the area of treatment. But there is continuing ignorance which leads to a failure to implement such knowledge as we already possess, both in prevention and in treatment. How do we ensure the education of mothers-to-be, who through our failure to provide appropriate staff-training and related resources are about to leave our schools as 'failures'?

Our organization, which together with its allies in this field has up to two per cent of teaching force within it, must plan not only to multiply this total membership by at least eight, but to go beyond this towards influencing the vast majority of teachers. Warnock now provides us (and others) with the stimulus and perspective, to align with and mobilise all the professions concerned with pre-school education; all the organisations, professions and colleagues who are concerned with the education of handicapped pupils in our ordinary and special schools; all those who are concerned with post-school opportunities for handicapped leavers and their post-school education.

INTO THE 1980s

Given the right vitamins we shall accomplish proper division and multiplication of cells such as will make the achievements of special educators and parents in the 1940s, 1950s and 1960s seem small by comparison.

As we move towards 1981, the International Year of Disabled People, an impressive increase in the membership of NCSE will reflect, as well as contribute towards, changing attitudes within relevant professions; collaboration, interdisciplinary enrichment, and new ways forward.

Local authority officials and colleagues in key positions in the special services, may wish to consider ways in which they might help publicise within ordinary schools the work of our branches, thereby making fuller use of our local and national resources without cost. This in turn will enable NCSE to increase its resources and intensify its contribution to national and local developments.

We must not overlook the potential allies we have in the local media and local press.

We must encourage more and more of our special schools and remedial classes to move on from being oases for refugees from our large classes or from inadequately trained staff; we must help them to reach out; to become demonstration centres; to offer an advisory service; to be seen as a form of back-up service and encouragement to those colleagues in ordinary schools and classes who have more satisfaction in picking winners, as well as to those struggling colleagues who value all pupils and seek only the skills and the means to help enrich them all. We must emulate what is already being done by our best schools. As ordinary schools become increasingly represented within our membership and amongst our subscribers, the children with learning difficulties in ordinary schools will be less likely to be rejected and will benefit from changing attitudes as well as from improving skills. In this way realistic forms of integration will evolve, *based on the kinds of value which gave rise to the drive for normalisation and community care.*

We must consider the growing evidence advanced by Professors Chazan, Mittler and others of the role which parents have to *play, of parents as a resource and as members of a team.* We must help colleagues to find ways of overcoming the problems such policies invite, in search of the wider good. We must consider new initiatives in staff-training and I must say how impressed I was by the initiatives of the Association of Professions for the Mentally Handicapped and by the British Institute for Mental Handicap amongst others, to set up models or units of in-service training which can be provided in different parts of the country. Many colleagues will recall the time when normal teacher training was extended from two to three years, and such generically trained teachers were expected to spend five years teaching in ordinary schools before they were permitted to go on a relevant one-year diploma course to teach ESN or maladjusted children. A strong case was advanced for such a sequence of experience and training, despite the fact that it meant that the vast majority of teachers did not get the specialist training and the vast majority of handicapped pupils today still do not have specially trained teachers.

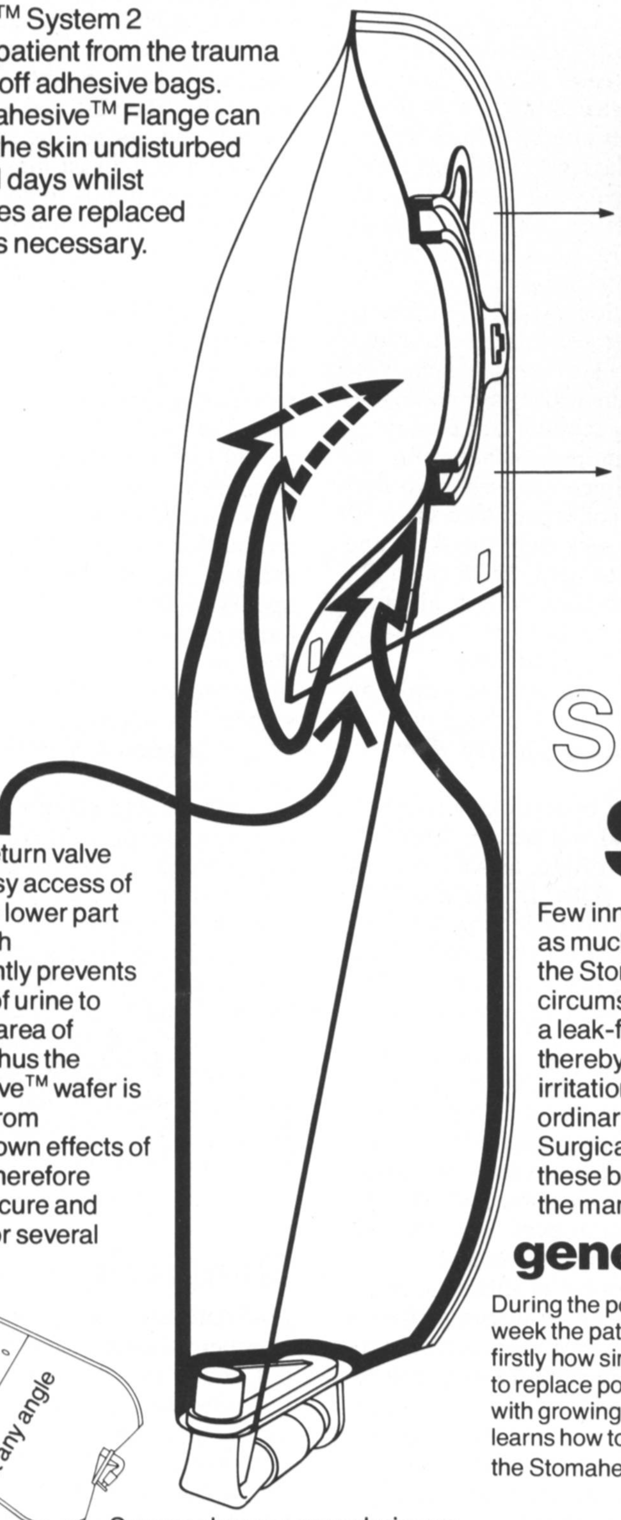
At the same time, outside the education system, the children we had excluded were being taught by the staff who at best had a two-year training, *but this training was specifically directed to the work they had to do.* It was during this period that the parents' organisation were persuaded to set up their own college, to train from scratch for mentally handicapped children, students who would qualify as Burnham teachers. It required enormous courage for them to do this—against the trend. Their initiative in fact overlapped with others which brought us the 1970 Education Act earlier than might otherwise have occurred. Westhill College promptly adapted to a new decade's opportunities and our debt to the parents organisation took a new form.

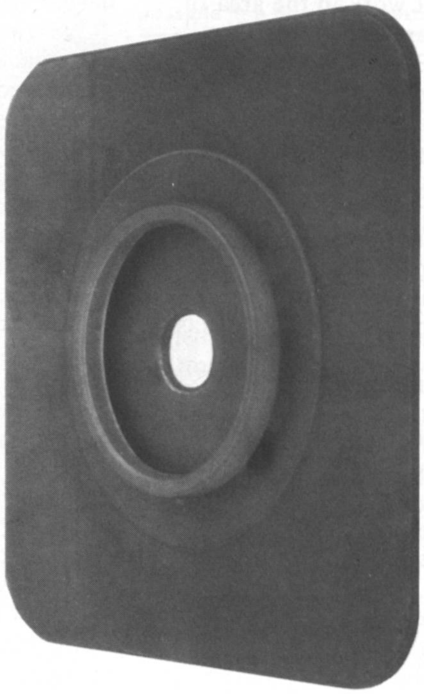
We have a great deal to do in the 80s. Let us first set the targets in each branch for 1981, the International Year of Disabled People. Let us keep in mind in these days of biting winds that the values for which we stand, and the children whom we serve, can never be made redundant.

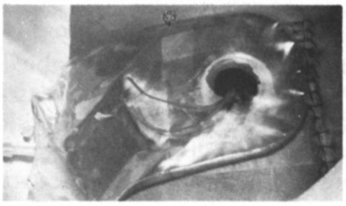
Handicab venture

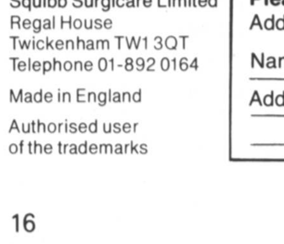
HANDICAB is a 24 hour commercial mini-cab service based in London and run by handicapped and able-bodied people. As well as ordinary vehicles HANDICAB has available a specially adapted van with a hydraulic tail-lift for wheelchair access so that people with electric wheelchairs, and those who cannot transfer to an ordinary car seat can also travel comfortably.

For further details and rates ring HANDICAB on 01-960 6144 or 01-579 9679, or write to them at 95 Sixth Avenue, London W10 4HH.








Secure
at any angle

Here's a key to the future

DWIGHT C. Baker, from the USA, gives us a timely reminder that the problems of the disabled are international. Timely, because 1981 is International Year of Disabled People. LINK would like to hear from many more of its overseas readers so that during 1981 we can give the magazine a truly international flavour. Photographs (which will be returned) will be welcome.

I WANT to tell you a little about myself. I live in Bryan, Texas, in the U.S.A. and I have spina bifida.

I do know of two people who have spina bifida who are able to walk without any support, but I am not as fortunate as they are. I have to use braces and crutches.

But many handicapped people, like myself, can do the unexpected. For example, last year I walked 17 miles in a "walk-a-thon" sponsored by the "march of dimes" to raise money to help stop birth defects. I have also done a little bit of research into spina bifida, and have won two first prizes at the science fair. I have also won two second prizes in speech contests. I sing in my school choir, and take part in school plays, and as many other activities as I can.

Spina bifida kids can become lawyers, doctors, authors, President of the United States (or a leader of some other country), plus many, many other things! But, in order to do all these things, handicapped people need a good education.

In my school I cannot get to the library or to the cafeteria. When I have a paper to write, I have to use the public library, because the school library is upstairs and there is no lift or elevator. And I cannot eat with my peers, because there are also stairs to the cafeteria. Another handicapped boy and I eat together, alone.

But the law (in the United States) says that all public buildings should be equipped with devices fit for everyone, students and teachers as well! Is there anything we can do about all this? Yes! You can talk to someone on your school board and ask them to see that devices are installed in your school so that you can get around faster and easier.

But let's not forget the teachers. Yes, they can help us, too. But sometimes they do, or say things, that embarrass us and make us feel very, very bad! In our country there are kids with other kinds of problems, too, such as being very poor or speaking another language. And there are people (I am also one of these) who have some trouble with handwriting, because of some physical handicap. All these people need help and understanding, too.

Handicapped teenagers need a good education so we can get good jobs, so that *our* kids will be able to get good educations and jobs! Why? Because kids (whether handicapped or not) are *people*, too!

In support of selection

MAY I support wholeheartedly Professor Lorber's views on the dignity of amniocentesis testing and the selection of babies with spina bifida, with consent of parents.

I was born before either pre natal testing or selection, when babies born with spina bifida were, on the whole, untreated. Those who survived did so by natural selection and were on the whole, like myself, of very strong constitution and able to make considerable progress throughout the years.

Those of my age who made it may have had numerous operations etc. but are mainly those who could cope. The fact that hydrocephalus was untreated and therefore either self arresting or fatal eliminated many of the hydrocephalic problems encountered later.

I have witnessed many treated children in the early years of treatment with a poor prognosis of life who suffered, along with their families, until their eventual and inevitable death, causing much distress. Likewise I have witnessed treated children who have become valuable integrated members of society.

As a third child I grew up in a loving, caring family home where my disabilities were accepted.

I have neither parent living to speak about my life, having lost both many years ago. However, I have two sisters who have between them, thankfully, five healthy children, all now adult. Both sisters are with me on my views that they would have had no hesitation in having an abnormal pregnancy terminated had the test been available to them.

We are a very close family where I am accepted for myself but I can assure you that my nieces and nephews are aware of the hereditary factor in spina bifida and hydrocephalus. Should they be prospective parents they will have the amniocentesis test carried out and any abnormal pregnancy terminated.

My family know at first hand what the effect of a spina bifida child has on the child and the wider family. Whilst they can see me as an adult with a good life, a good career, and only slight disability compared to many, not one of them would like to see it happen again in our family. They would be the first to say that the abnormal pregancy should be terminated.

FAITH M. SEWARD B.A.

Study days on sport

THE DISABLED Living Foundation, in association with the Sports Council, is organising a series of one-day study sessions 'Sport and Physical Activities with Mentally Handicapped People Living in the Community'.

The first is in London on October 7 at the London Hospital Medical College, Whitechapel. This will be followed in November by one in Avon and there will be others during 1981.

Further details: Miss Margaret Dowden, Conference Secretary, DLF, 346 Kensington High St, London W14 8NS. Send 9″ × 4″ s.a.e.

Come on you youngsters —use your initiative

CALLING all young people . . . Have you started on a sponsored initiative for ASBAH yet either on your own or as part of a school or club group? If not there is still time to send for your form and get cracking.

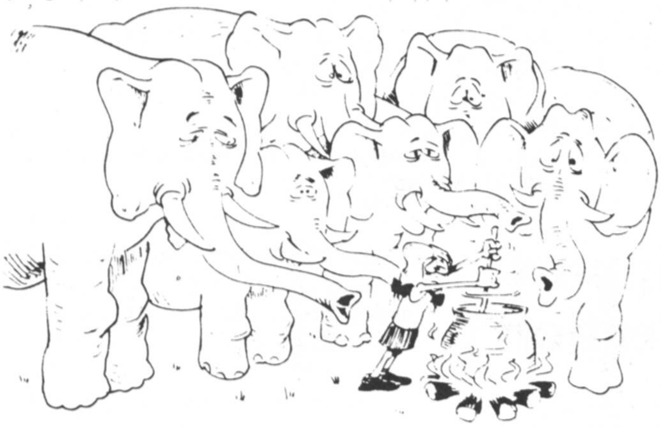
Esther Rantzen is backing the appeal and the idea is that young people all over the country will use their wits, imagination, stamina and muscles to raise much needed funds for ASBAH's work which will help young people with spina bifida and hydrocephalus.

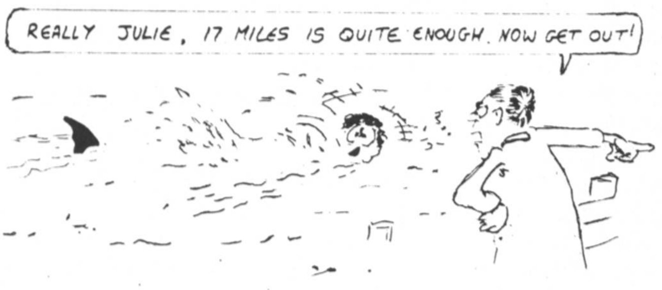
ASBAH has a list of suggested projects with the number of points each project will earn you and you then get people to sponsor you for so much for every point you gain.

Here are some of the suggestions:

Age group 16 plus:

One mile swim (11 points); cook a dinner for six (9 points); obtain a signed news sheet from a newsreader (11 points).





Age group 11-16:

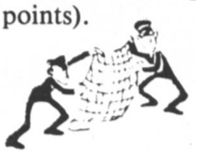
Wash five cars (9 points); half an hour on a submarine (13 points); make a toy (8 points).

Age group under 11:

Obtain a pre-decimal coin (11 points); wash up (6 points); get 10 things into a matchbox (8 points).

All age groups:

Shake your MP's hand (9 points); plaster cast of two animal footprints (10 points); plant a tree (10 points).



The list is much longer than this of course.

In order to recognise your achievements and concern for others, ASBAH is offering awards for certain levels of sponsorship reached. If you raise £2.50 you will receive an ASBAH badge, and there are other awards for up to £20 raised. For £20 you will receive a super ASBAH T-shirt.

The participant raising the most within each school or club will receive a special award and the school or club will also get a certificate for taking part.

Write *now* to ASBAH Appeals Department at National Office for a sponsorship form.

Top club backs ASBAH

BLAZER's of Windsor, now one of the UK's top night clubs, is holding a Gala Charity Night in aid of ASBAH on Tuesday, October 7. The star of the cabaret show is the ever popular Danny La Rue. Tickets are £8.50 and are inclusive of a three course meal. They are available from Madeleine Legg, "Thriftswood", Stevens Hill, Yateley, Camberley, Surrey GU7 7AZ. Tel: Yateley (0252) 872356.

It is possible to book whole tables of up to 12 people, so bring along a party and enjoy what promises to be an evening full of entertainment.

JUDY KAY

CLASSIFIED 'ADS'

The advertising rate is:
£1.50 for up to 30 words. £2.50 for 30–45 words.
£3.50 for 45–60 words.

Please send remittance with your advert. You may like to pay for a whole year's advertising in one go.

Adverts for the next LINK (Sept/Oct) should be in by August 5. Send to the Editor Mrs Susan Gearing (or telephone her on Langton 3351).

HOLIDAY ACCOMMODATION

CAMBER SANDS: Well-equipped and adapted chalet (sleeps 6). Bookings taken by Mrs N. Kerswill, 28 Ilmington Road, Kenton, Harrow, HA3 0NH. Tel: 01-907 8526 (2–7 pm).

HEYSHAM, Nr Morecambe: Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 9 Belton Road, Whitchurch, Salop. Tel: Whitchurch 3691.

MABLETHORPE, Lincs.: 2 well-equipped 6-berth chalets, self-contained, at Mablethorpe Chalet Park, Links Road. Details: Mr. B. Guest, 57 Bloxwich Lane, Walsall. Tel: Bloxwich 31725.

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

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

FOR SALE

Leisure Wear: White cotton **Tee Shirts** with green Family symbol and words 'Support Spina Bifida' £1.60 each size 2"–30"; £2 each small, medium, large. Also quality **Sweat Shirts** with reverse colours in all sizes including extra large adults. All at £4.50 each plus postage. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

LINK RATES

These are the rates for subscribers to LINK who obtain their copies direct from national office:

U.K.	£1.85
Europe (surface mail)	£1.75
USA, Canada (surface mail)	$3.85
USA, Canada (air mail)	$8.25
Elsewhere (air)	£4.10

The rates are per annum, and inclusive of postage and packing.

Local Associations changes

THE FOLLOWING changes of Honorary Secretaries have taken place since the last LINK. A full list of Associations will appear on the back of the next issue:

BRISTOL
Mrs Mabbutt,
20 Bramble Drive,
Stoke Bishop,
Bristol.

JERSEY
Mrs Z Ritchie,
Magnolia Lodge,
Magnolia Gardens,
Bel Royal,
Jersey.

SOMERSET
Mrs B Edwards,
Bur View,
Churchway,
Curry Rivel,
Langport,
Somerset.
Tel: Langport 251273

ASBAH booklets etc . . .

Your Child with Spina Bifida, by J. Lorber, MD, FRCP	25p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP	20p
Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH	30p
The Care of an Ileal Conduit and Urinary Appliances, by E. Durham Smith, MD, MS, FRACS, FACS, and others	15p
Aids and Equipment	60p
Sex and Spina Bifida by Bill Stewart	£1 (75p to LIFT members)
The Handwriting of Spina Bifida Children by Joan Cambridge and Elizabeth M. Anderson ...	£1
The Nursery Years by Simon Haskell & Margaret Paull	35p
Information leaflets	100 for £1.30

All available from ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 15p per booklet.

Scottish Spina Bifida Association Booklets

Growing up with Spina Bifida	30p
The Spina Bifida Baby	30p

both by O. R. Nettles, McSP, ONC.
Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

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All available from Appeals Dept.—postage extra.

Film 'Appeal for ASBAH' 10 mins **16 mm Colour/Sound**	**£4 Hire**

The Appeals Dept. carries a range of fund-raising items, i.e. pens, key rings, kits, games, etc. Send for list and order form.

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

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