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Association for Spina Bifida and Hydrocephalus/ASBAH 10p Mar/Apr 78

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Association for Spina Bifida
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Tel: 01-388 1382/5

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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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Information Officer:
Miss B Holland

LINK Editor:
Mrs S I Gearing

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IN RECENT WEEKS there has been much controversy about the care of new-born spina bifida babies.

Some who favour selecting babies for operation, and allowing others to make the best of what chance nature has given them, point to the fact that almost 100 per cent of the babies who do not undergo operations die. They see this as proof that the situation was hopeless from the start. Others challenge this, alleging that drugs are sometimes administered to the babies not selected which induce sleepiness and a lack of interest in food; death usually follows in a matter of days or weeks.

Writing in the British Medical Journal, Prof. R B Zachary illustrated the issue starkly—''In another centre only one out of 24 patients was operated on—all the others died. When asked, 'Did they fall or were they pushed'—into death—the reply was, 'They were pushed, of course''. Prof. Zachary, resolutely opposed to such action, went on to pose the question, ''Are not these actions outside the law?''

Best care available

The answer to that question must be—''Yes''. Selection for treatment for some must not lead to neglect and death for others.

Any new-born child must receive the best care available. In certain circumstances this care may add up to love and affection and a decision that nature should take its course. There is no merit in treatment for the sake of treatment. But nature must not be pushed, or directed in such a way as to hasten the death of a new-born child. A child who has survived thus far must be allowed the chance to defy the odds and live.

Echoes of the past

Increasingly entangled with this issue are echoes of the anti-abortion debate. Some would argue that legalising abortion was the thin end of the wedge; that disregard for life within the uterus continues into post natal life. There is, however, many people would recognise, a real distinction between the two controversies.

In law man has decided that he can draw a line—to say ''so far, and no further,'' and recognises the distinction between a few weeks old foetus and a new born baby. It is a distinction encompassed in the Abortion Act 1967.

And therefore when a chronic handicap can be detected at an early enough stage for the foetus to be safely aborted it is only right that the option should be extended to the parents so that they can make their own personal and painful choice. Some dispute this, arguing that from conception life must be preserved.

A personal choice

The nub of the matter is—it must be a personal choice. It is the parents' life, the life of their family which is in a very real sense at stake. Society still neglects the needs of the handicapped, passing the major share of any burden to individual families, to such an extent that it has no right to impose a decision on abortion one way or another. It should be remembered also that there is a very positive side to prenatal testing. It has made it possible for some ''at risk'' women who would otherwise have been sterilised to conceive and give birth to healthy babies.

And so there are two aspects to the present controversy. They can be linked, but are separate. A child who survives to be born deserves the best care society can provide—right through his life—even though, had the extent of the handicap been known earlier, the option of an abortion should have been extended to the parents.

—EDITOR

Cover Story

A "Magic" moment for 11-year-old Nicola Bailey (see Front Cover) as she receives a surprise present of a pony. Nicola who has spina bifida and hydrocephalus and lives in Nantwich, Cheshire received one of the Children of Courage Awards, sponsored by a leading women's magazine.

After receiving the award she appeared on the television programme 'Nationwide', and during an interview with Frank Bough told him that she liked horse riding but didn't have a pony of her own.

One of those watching the programme was Mr Roy Butters a hay and straw merchant from Norfolk, and he decided to give Nicola a special present—a pony of her own called 'Magic'.

In the picture Mr Butters' daughter, Amanda, is handing over 'Magic' to his new owner.

Photo: Stoke on Trent Evening Sentinel.

● See Letters Page 5 for a letter about Nicola written by her mother.

Bus travel

A LEAFLET, *Concessionary Fares (Bus travel),* **has recently been published by the Department of Transport (2/78), and Welsh Office (8/78). A copy is available for reference at National ASBAH.**

Among other things, the circular recommends that invalid chairs should be carried free, and that local authorities should consult with voluntary organisations who are 'best placed to explain their members' needs'.

■ ■ ■

ASBAH has also been assured that work is continuing on modification of buses, and that the Ministry will keep them informed.

Benefits

STATISTICS of people receiving various benefits in the year 1977/78: Attendance Allowance Higher Rate 146,000, Lower Rate 137,000. Mobility Allowance (to Oct 1977) 57,000. Invalidity Benefit 452,000. Non-Contrib. Invalidity Pension 130,000. War Disablement Pensions 309,000. Industrial Disablement Benefit 201,000.

Publications

THE DISABILITY Rights Handbook for 1978 has been updated from last year's edition, and is available from the Disability Alliance, 5 Netherhall Gardens, London NW3 5RJ. Price 75p including postage.

■ ■ ■

Dorcas—"Opportunity, not Pity" is written by Dorcas Munday, who is herself handicapped and has been a member of PHAB for over ten years. Available from PHAB, 42 Devonshire Street, London W1, price £1.10 including postage.

A GUIDE to the Mobility Allowance produced by RADAR (The Royal Assoc. for Disability and Rehabilitation) has been revised. It includes a list of concessions available to disabled drivers and passengers. Please send a large SAE for a single copy; further copies are available at a cost of 10p each, from RADAR, 25 Mortimer St, London W1N 8AB.

THE CINDICO Traveller pushchair is now available free on loan through the National Health Service for some handicapped children.

The chair provides very good support, folds up quickly and easily and can be carried over one arm. Ask your doctor's advice about whether it would be suitable for *your* **child.**

Buildings survey

THE CENTRE on Environment for the Handicapped is to establish a national register of buildings designed or adapted for the handicapped, for reference by architects, planners etc.

The Centre needs information on day centres, schools, hostels, group homes, public buildings, housing or other projects. If you can help with this survey by completing a simple form about a building near you, contact Ros Purcell at CEH, 126 Albert St, London NW1 7NF. Tel: 01-267 6111. Ext 264.

Conferences

ASBAH's ANNUAL GENERAL MEETING this year will be held on Saturday, October 14 at the Bowater Theatre and Conference Centre, Bowater House, Knightsbridge, London.

The Centre is easily reached by public transport, and there is adequate free parking under the building. The suite of rooms being used for the meeting is accessible to wheelchairs. More details later.

■ ■ ■

'SIXTEEN Plus and Handicapped—Education for Living Conference'. June 13, Royal College of Surgeons, London. This Conference, to examine the needs and problems of handicapped young people of 16 plus to see what further provisions can be made for them, is being organised as part of Friendship Week for Sick and Handicapped Children.

Fee £7.50, inclusive of lunch and tea. More details from Mrs V Abrahams, 3 Totternhoe Close, Kenton, Middx. Tel: 01-907 3024.

Radio

Radio London (206 Medium Wave) has a special information spot for the disabled every Wednesday morning from 11 am. There are two programmes which alternate each week—LINKLINE which aims to give general advice and information on all topics concerning disablement, and NETWORK which specialises in legal problems.

What many people don't know is that after the programme there is an off-the-air phone-in session lasting through until 3 pm. Listeners can ring in and discuss their problems in complete confidence. The telephone no.: 01-486 4070.

We must be allowed to run risks

AS A PHYSICALLY handicapped person I would like to comment on the article "Growing Pains" in the December issue of LINK, outlining Dr Greengross's talk on the problems of growing up.

I thoroughly agree with her on the subject of independence; as someone said "the physically handicapped are people with physical handicaps not physical handicaps with people attached". I firmly believe that every physically handicapped person should be allowed to live as full a life as possible, however costly this may be to them and their parents. Let's face it, all independence involves a risk.

During my school years I attended both a special school and an ordinary school, then after school I went away to a college for the physically handicapped at Coventry for a year. There I had a few costly lessons in independence. My mother didn't tell me before I went, but when I left college she told me that letting me go away was one of the hardest things she ever had to do.

In the past year I have written my autobiography and I have to face the fact that it might not be published, but it was something I felt I wanted to do. As I find it impossible to get employment I decided to turn to writing, which I find an invaluable outlet.

As far as sex is concerned I cannot agree with Dr Greengross completely. As a Christian I believe that my body is God's property and therefore I could not contemplate a casual relationship of any nature. On the other hand I would be happy to marry if the right partner came along, someone with similar handicaps to my own and someone who shares my faith.

I should be pleased to hear from any young people (either sex!) who share my views on this subject. I am twenty two and a hydrocephalic.

JENNIFER HILL
62 Waterloo Rd, Penylan,
Cardiff, CF3 7BH.

LETTERS, letters, letters . . . they are starting to flow into the LINK office. Please do let us have more of your letters—with news, views and comments. A good Letters Page is at the heart of any good, lively magazine.

Please mark them 'For Publication'. Letters for May/June LINK should be with me by April 1. SUSAN GEARING. Editor.

Courageous Nicola keeps on smiling

I AM SURE that Nicola's story could help some parents to see the pleasure that these children can get out of life, given the chance—also the love that you get from them. I know it's very hard work and heart-breaking at times.

Nicola is both a spina bifida and hydrocephalic child, who is very happy and contented and who lives life to the full. She enjoys horse riding, swimming, baking and dancing in her wheelchair which she does on a Saturday night when all the family go out together. Nicola goes to church every Sunday morning and was being confirmed on March 1.

She is always smiling and happy and I think this is what won her the award (The Children of Courage Award, see page 4). She tries so hard to do things for herself, because we have no facilities at all for her which makes things that much harder.

Magic is a beautiful pony and for Mr Butters and his family to give her to Nicola was a wonderful thing which will never be forgotten. Magic is stabled at Broomhall Riding School where Nicola used to go riding before she went to her new school. She is the star of the stables.

Nicola and Magic are getting on very well together and she is getting used to the wheelchair. Magic is quiet and just right for a child like Nicola.

MRS J BAILEY,
Nantwich, Cheshire.

INTERMITTENT CATHETERISATION

We are thrilled with method

I WAS very interested to read the article in your November issue on Intermittent Catheterisation.

Our daughter Rachel was born in Toronto, Canada, four years ago and has been on intermittent catheterisation since she was eight months old. At 15 months she had her ureters re-emplanted to correct reflux that, prior to catheterising, had already caused deterioration to one kidney. Catheterisation is now used quite widely in Toronto on both boys and girls.

Rachel is catheterised every four hours until last thing at night and we use clean (as opposed to sterile) conditions for the catheter. Rachel does have some feeling around her bladder opening but this procedure has never caused her any discomfort or distress. It keeps her dry and enables her to be out of nappies.

When she was a baby we used to catheterise her lying down but now she just sits on the toilet which means she can be easily attended to when we are out anywhere. She is already showing an interest in learning to catheterise herself.

Since Rachel has been on this method she has been free of infection and recently has not needed antibiotics. Also X-rays tell us the condition of the bladder wall has improved.

When we returned to this country to live we were happy to find a urologist who was quite in agreement with our continuing this method of treatment. We are thrilled with this whole process which we find easy to manage.

Like Mrs Moore we would be happy to discuss this further with anyone who may be interested.

BRENDA MURRAY
1 Nuthurst Grove, Bentley Heath,
Solihull, W. Midlands B93 8PO:

IF YOU are somewhere between the ages of 13 and 25 and are trying to overcome the problems of having spina bifida or hydrocephalus, and are needing a bit of a LIFT, then read on...

LIFT gets going for young spina bifida adults

LIFT is the name of the young ASBAH group which has recently been formed because of the growing feeling among young people with spina bifida that they would like a 'platform' 'a club', 'an organisation'.

Over 200 young people have responded so far, but there must be many more who could get something out of LIFT.

It has produced its first Newsletter, so if you would like a copy, or more details of LIFT, please write to LIFT, ASBAH, Tavistock House North, Tavistock Square, London WC1H 2HJ.

LIFT wants to hear your news, and views and ideas for future Newsletters and activities. One of the first projects has been a residential week at Five Oaks, ASBAH's home at Ilkley, Yorkshire, emphasising personal independence at home and at work.

The co-ordinators of LIFT at National Office are Barbara Newman (Education, Training and Employment Officer), Jill Vernon (Aids and Appliances) and Beverley Holland (Information Services).

Students have a taste of working life

CONEY HILL School, Hayes is asking local employers to give senior pupils at the school a chance to sample working life as they reach the end of their school days.

Headmaster, Mr Terrence Lane told the Beckenham and Penge Advertiser, "They need to prove to themselves they can hold their own with ordinary school leavers.

"They come back to us as completely different people, as if they had grown up overnight".

Four seventeen-year-olds with spina bifida have been out and about getting a taste of working life. One of them, 17-year-old Stephen Cooper is pictured with three girl colleagues during a month at Duckhams Oils.

Photo Duckhams Oils

PRETTY as a picture—young Julie Ann Carleton one of the younger members of the Belfast Association on the day she was flower girl at the wedding of one of her classroom attendants at Fleming Fulton School.

Julie has recently been fitted with full leg calipers and is reported to be managing very well.

Centre opens up the Lakes

THE AIMS of The Calvert Trust Adventure Centre which opens in April this year is to provide facilities for disabled people to enjoy the Lake District National Park, as far as possible, in the same way as able bodied people.

The Centre is built in traditional Cumbrian style, and is set in two acres of grounds over-looking Bassenthwaite Lake, and below the mountain range of Skiddaw, 931 metres. It commands a beautiful panoramic view of the nearby fells.

The Centre is open from mid-January to mid-November for archery, angling, birdwatching, riding, hill-walking and nature trails, while between April and September, sailing and canoeing will be added to the programme, thus offering facilities for purposeful and enjoyable community life throughout the year.

Suitable

The accommodation is suitable for both sexes, in mixed groups, and is specially designed for wheelchair usage. Twenty-seven people can be accommodated in pleasant two bedded rooms, with adequate bathrooms, showers, toilets and drying rooms; two dining rooms, a lounge (with T.V.), a games room and a shop complete the accommodation.

A key purpose of the Centre is self sufficiency. The Course members will cook and cater for themselves in the fully-equipped kitchen. Food stores may be purchased from the warden.

Further details of course fees, etc., can be obtained from: E. M. Evans, Warden, Calvert Trust Centre, Little Crosthwaite, Underskiddaw, Keswick, Cumbria CA12 4QD Tel: (0596) 72254.

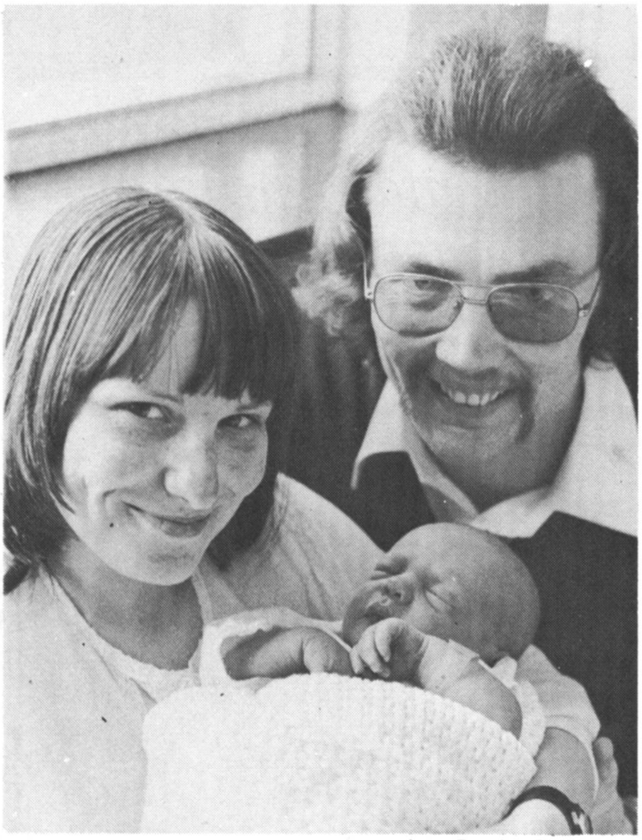


photo Evening Post, Leeds

Lyn and George Bailey with baby Adam.

Announcing the birth of two very special baby boys

THE BIRTH of a baby is always a time for a special kind of happiness and when, within 48 hours of each other, in Aberdeen and Leeds, two spina bifida mums gave birth to healthy babies—that's extra special.

In Aberdeen Brian and Sandra Horne became the proud parents of a 5lb 5oz baby boy, Greig Mackinnon Baxter.

The Aberdeen Evening Express quoted a spokesman at the Aberdeen Maternity hospital as saying it was a normal birth without any complications. Nineteen-year-old Sandra uses a wheelchair but whenever possible tries to get around on her crutches.

In Leeds, the Evening Post newspaper reported that Lyn and George Bailey were "over the moon" about the birth of baby Adam Richard who weighed in at 8lb 2ozs. The birth was by caesarean section.

Lyn and George were married in December, 1976 after meeting at the Remploy factory in Pontefract. George is able-bodied.

When Lyn, now 22, was born it was feared she would never walk and she had to endure a series of operations. Her husband was quoted as saying, "Lyn had a very difficult time up to the age of 15 but since she started work she has been able to lead as normal a life as you can expect with someone of her condition."

EXPLORING BRITA

The youngsters were never bored—how many holidays can boast that?

IT'S THE pace of life, the general stability of the boats and the beautiful surroundings which go to make cruising on Britain's inland waterways an ideal pursuit for disabled people.

In a special booklet, "Water Sports for the Disabled", the Sports Council point out that those whose disability is not too severe can help the crew. Even those who are totally immobile can be transferred on board on stretchers for a few hours enjoyment.

Britain's narrow boats—once used for carrying cargo along the canals and waterways—are the most suitable craft for the disabled. Their overall dimensions, about 12 m long and 2.2 m wide, provide scope for conversion for more leisurly activity and space enough to meet the needs of the disabled.

Most of them are privately owned so special bookings have to be made but there are now organisations catering specially for the disabled (see page 9).

Peter and Margaret Povall, members of Hull and District ASBAH, together with a mixed party, proved for themselves just how enjoyable a canal boat holiday can be . . .

DURING the Autumn we set off with two interested friends and Susan, 9, Colin, 7, and Alistair, 14. Both Colin and Alistair have spina bifida and hydrocephalus.

We chose the Leeds-Liverpool Canal from Skipton because we had experience of it. The scenery is particularly beautiful and you are never far from a telephone should there be an emergency.

A very happy, healthy week was had by all and we are planning two further trips with a bigger boat in the spring.

Our boat was 54 feet long and equipped with central heating, flush toilet, shower, TV, full size bunks, fridge, large living space and a well planned kitchen.

The youngsters were never bored for an instant and how many holidays can boast that?

There were some problems. The steps at either end of the boat were OK for Alistair but beyond Colin. None of the youngsters could reach the steering, even using chairs. *(We expect the boat hire firm to provide us with a platform next time)*

We would have liked more bathroom space—although we solved this by arranging the doors in such a way as to take part of the corridor and still retain privacy. *(The boat we will use in the spring has two toilets).*

There are opportunities for map reading, rope handling, bird watching, photography, fishing, sketching as well as boat housekeeping. Everybody helps with the chores.

The cost of an eight berth boat ranges from £130 per week (plus VAT) off season to £330 (plus VAT) during the high summer. The total cost for food and other provisions would be about £50 for eight people.

■ **Mr and Mrs Povall have two short films and many slides of the holiday which they would be happy to loan to other Associations. Please write to Peter and Margaret Povall, "Horseshoe Cottage", Shiptonthorpe, York, YO4 3PE.**

The *Matilda* and *Minuet* keeping each other company—both of them are kept busy giving handicapped youngsters a good time on the river.

Other ways of enjoying water

IF YOU want some more ideas on how to enjoy the water even if you are spina bifida, or have a spina bifida youngster, then a perfect book to get is *Water Sports for the Disabled.*

This well-illustrated, easy-to-read handbook was produced last year by the Sports Council's Advisory Panel on Water Sports for the Disabled.

The Foreword states "Whatever your aspirations, this handbook gives a new dimension to water sports for the physically handicapped and an abundance of expert advice and encouragement."

Price 50p from: RYA Publications, Victoria Way, Woking, Surrey, GU21 1EQ.

Abov
the e

Belov
lots t
The *M*
River

IN'S WATERWAYS

Special boats give hundreds a taste of life afloat —and the trips are free

e: on the way upstream, the passengers enjoy
xperience of waiting in one of the locks.

v: the sun is shining, the river is busy, there's
o see . . . and we are having a good time.
Minuet going under one of the bridges on the
Soar.

WITH willing helpers available the handicapped can enjoy trips on standard boats. But if the boats can be specially designed or adapted the scope for enjoyment is enormous.

In the East Midlands and in mid Wales such special boats are already introducing hundreds of disabled people to the joys of Britain's waterways.

The *Minuet* and the *Matilda,* both purpose-built narrow boats, will be found at the Plus Pleasure Marina at Shardlow in the East Midlands. Both are kept fully busy giving free day trips to the disabled.

The boats are operated by the Peter Le Marchant Trust which exists to give free trips on waterways to handicapped people.

The Trust began in 1976 with one boat which was soon fully booked for its operating season. The *Minuet,* with its hydraulic lift for wheelchairs, was introduced in 1977 and in late 1978 a third boat will become available. This will enable the Trust to offer overnight trips and holidays.

The boats are crewed by police cadets from Nottinghamshire and Leicestershire, housewives and other volunteers. Other organisations, such as the Inland Waterways Association, run trips at the weekend.

The boats are in heavy demand so would-be trippers should book. Contact Mrs Clare Hanmer, Peter Le Marchant Trust, Colston Bassett House, Colston Bassett, Nottingham. Tel: Kinoulton 424 (STD 09497).

■ In mid Wales on the Montgomery Waterway a specially designed canal boat *Heulwen* (Sunshine) offers free day trips to parties of handicapped children. *Heulwen* is operated by the Prince of Wales Committee in conjunction with the Variety Club, and is supported by HRH The Prince of Wales.

This 70 foot narrow boat can carry 11 children and nine nurses, with a paid crew of two. It is equipped with two toilets, a stainless steel galley, treatment table, hot and cold water and a telephone. Local telephone engineers have given a cash fund for the children to phone home from the boat if they wish.

Heulwen operates daily from Monday to Friday from Welshpool. Hospitals and organisations can book the boat for a day or more at any time they wish, so it pays to book early.

On each trip there are two local volunteers to help with tea making and washing up. They do not help with nursing.

For more details, and booking forms contact Mrs Nancy Millington, Green Acre, Salop Road, Welshpool. (Tel: 0938 2563).

GARDENING can be therapeutic. Dr P. J. R. Nichols speaking to the Royal Horticultural Society said, "It may seem strange to discuss gardening as a form of medical treatment, but in effect it can provide an interesting and realistic activity which many patients can understand and accept." This applies both in the treatment of disability diseases and in rehabilitation after accidents.

Garden Club plans to go on growing

THE GARDEN CLUB was started in 1973 to encourage disabled people of all ages to enjoy gardening as a creative hobby.

One of the aims is to link disabled people, wherever they may be, with the outside world, by encouraging them to take an interest in a hobby which they can share with the non-handicapped.

Special tools

Gardening from a wheelchair or while walking with a stick is perfectly possible, particularly with the aid of special tools, and raised gardens.

The Garden Club also acts as a central source of technical information for anyone with gardening problems. The Club hopes eventually to be able to arrange outings such as visits to large gardens.

A quarterly newsletter is printed, and exchange of seeds, plants, cuttings, bulbs etc. is carried out amongst members. Tools and certain seeds and plants can also be bought through the Club at a slight discount. There is a large library of gardening books which are loaned free to members.

All this for 50p a year; 60p for a married couple; £2 group membership, or £15 life membership.

The Club is sponsored by the Gardens for the Disabled Trust, and for more details write to the Club Secretary: Mrs Pat Cooper, Goddard's Green House, Benenden, Kent.

The seeds to plant in the spring

SPRING is the time for sowing seeds and the small foil trays in which many foods are sold make good seed boxes if a few drainage holes are made in them. They are excellent for mustard and cress.

Soak the soil well, then after planting encase the tray in a polythene bag secured with a twist tie. Leave until the seedlings appear, when the bag can gradually be opened to admit light and air and finally discarded.

This technique can also be used for leaf cuttings. For plants such as begonias. Fill the tray with earth covered with a layer of sand and water well. Cut across the main vein of the leaf on the underside and then peg the leaf down onto the sand. A young Begonia Rex grown in this way is beside me as I write.

Succulents such as sedums do well if the stem of the leaf is stuck into the damp soil.

Remember too those faithful pot plants such as geraniums that flower bravely on through the winter in our homes, or the Christmas Cactus with its lovely December display. This plant will enjoy a spring clean with damp cotton wool to wipe away dust. They may need re-potting or merely renewal of the topsoil or a fertiliser. Many plants benefit from being put outside on a mild day or enjoy a warm Spring shower.

Weeds also grow vigorously in Spring and should be removed when small. If left they compete with plants for light, water and food and many become difficult to remove.

Where space is limited packets of seeds can be shared with friends. Dobie's do a Tiny Garden Collection of small amounts of ten different vegetable seeds. Failing this Alfalfa, Fenugreek and Mung Beans can all be grown in a glass jar covered with a nylon stocking secured with a rubber band and make delicious salads.

Lastly take the advice of one of my neighbours, a keen knowledgeable gardener and try to grow something new each year.

Best wishes for successful gardening in 1978.

PERSIS TALLENTS B.Sc., S.R.N.
Gardens for the Disabled Trust.

ACCESS IS THE KEY

Marion Thomas talks to Selwyn Goldsmith

author of ***Designing for the Disabled***

TO ANYONE who is disabled the key to acceptance in the community, and to a fuller working and social life, is access. Access to the home, the workplace, to public buildings, restaurants, places of entertainment. Without access there can be little social and personal contact—the world is indeed full of obstacles for someone with even a minor handicap.

This waste of potentially productive people, and the consequent inability of the disabled person to contribute to the community—to be a giver and not a taker—is at the root of Selwyn Goldsmith's long standing concern with trying to get planners, architects and their clients to look their social obligations squarely in the eye. And now, with the passing of the Chronically Sick and Disabled Persons (Amendment) Act 1976* and the recently introduced 'Adaptations to premises and equipment' scheme, the importance or access as it effects employment has been officially recognised.

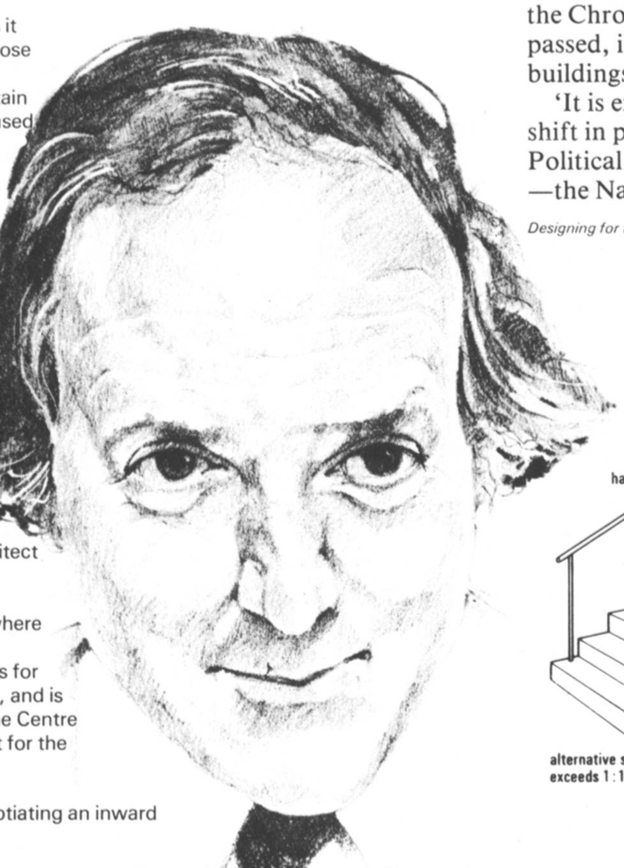
The key to successful integration, therefore, lies primarily in the architect's hands. The architect should be aware of the growing concern with disabled people's problems and try to design accordingly. Certainly, with the third edition of *Designing for the Disabled* on hand, there will be no excuse for clumsily placed doorways, narrow corridors, and posh entrances to public and commercial buildings, with no other access than a flight of unmanageable steps. Selwyn Goldsmith says,

> 'Perceptions are shifting . . . The notion that people should accept dreary, inaccessible workplaces is out . . .'

This change in attitude is reflected in the fact that when the Chronically Sick and Disabled Persons Act 1970 was passed, in its curious ad hoc fashion employment buildings were excluded.

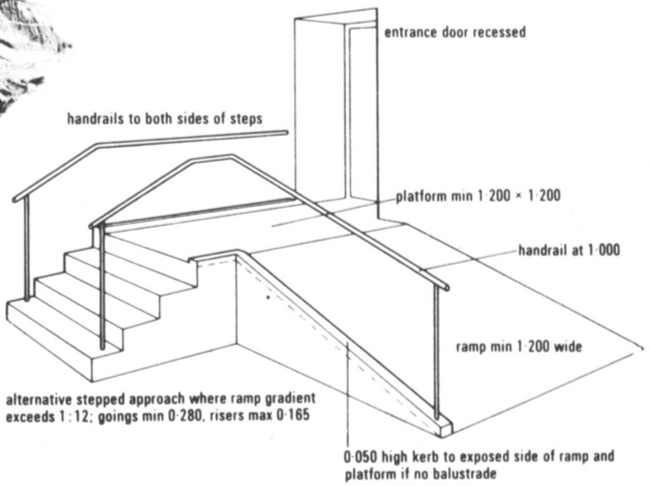
'It is encouraging that there has been this gradual shift in public awareness but I'm sceptical of its scope. Political awareness is still in advance of policy thinking —the National Theatre is a good example of this,

Designing for the Disabled (3rd edn.) RIBA Publications Limited £20. 1976

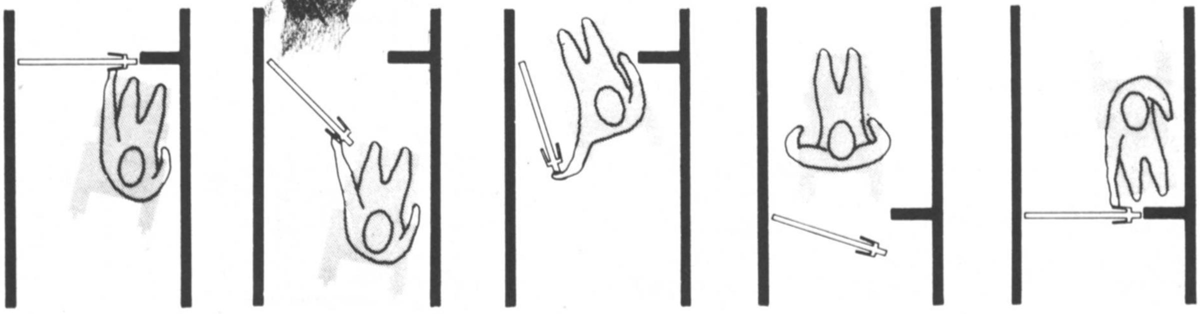


Selwyn Goldsmith is an architect in the Department of the Environment, where he advises on housing services for disabled people, and is consultant to the Centre on Environment for the Handicapped

Example of stepped and ramp approach for wheelchair users and ambulant disabled people



Spaces for negotiating an inward operating door



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*The Act makes it obligatory for those undertaking the provision of certain premises to be used as places of employment to provide access, parking and toilet facilities for disabled people

where provision for disabled people is, at the most, adequate—certainly not enough to encourage those in wheelchairs to drop in and see what's going on in and around the theatre complex, just like anyone else.'

But what about the extra cost of providing suitable access arrangements? Surely this is an important consideration? 'Obviously, overall economics dictate what can be done. For instance in a three-floor office block a lift would be an extravagance. There are inbuilt "cost penalties" in providing the kind of access we are talking about, but they are variable according to the size of the development. In a large development, the cost of the modifications advocated in the book would be minimal.'

> 'You can't evaluate the material return of access facilities.'

'Of course there are dilemmas for both architect and client for if there isn't enough wealth created then there are not enough goodies to go round.

'I'm increasingly concerned that society affords the physical apparatus for people who are severely handicapped, but although there is access, in its widest sense, in intention, and here we are more advanced in this country than anybody, in practice we fall behind. In Scandinavia, by contrast, things are done as a matter of course in terms of support for disabled people and their families.'

Certainly during the last ten years there has been a growing realisation that disabled people face tremendous problems in coping with a man-made environment designed for the able-bodied. It is generally accepted that disabled people should be given every opportunity to live full and independent lives, but in spite of this awareness improvements for employment opportunities, housing, education, and mobility have been slow.

The role of the architect in an all-round approach to the problems of disability is crucial. The architect should be aware of difficulties of access and how they can be overcome—not necessarily at greater cost to the client. Purpose-built houses for disabled people are now being incorporated into many private or local authority housing schemes. Adaptations to existing houses or flats are becoming more widespread. But as Selwyn Goldsmith says, what is the point of providing suitable housing if the disabled person cannot get to or into their place of work?

'The architect needs to understand in what ways the buildings he or she designs will help disabled people to opt in rather than perpetuate the custom that they are separated.'

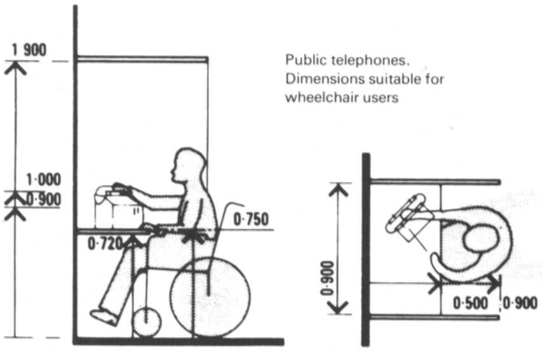
It is the architect who is able to influence the client who commissions the work. The architect should be aware of social pressures, changes of attitude, in varying evaluations of the 'normal'. It is the architect who designs, who is responsible for the finished product, whether it be a factory or an office block, a housing scheme or a theatre, and the architect's ultimate responsibility is the quality of living, working or participating within it.

The policy advocated by Selwyn Goldsmith is a pragmatic one.

> 'Our society is as it is; little by little we must endeavour to change it.'

'But not all disabled people have the resources to cope with everyday living—there must be opportunities, for opting out, for the sheltered environment.' But even more important, there must be opportunities for opting in, and that is the recurring theme of this book. There must be opportunities for disabled people to be involved in everyday life, to do the same sort of things that other people do. To do this, they may need adjustments to their surroundings, but this is in no way demeaning. It does not debase a deaf person to make sure they have adequate light at work to lipread, for instance.

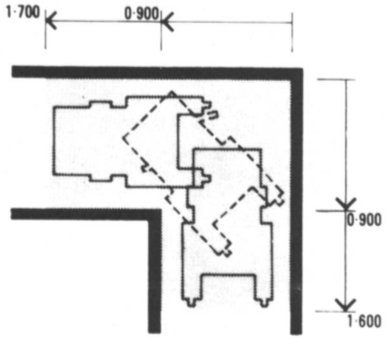
Certainly there are difficulties which the disabled person has to try and overcome, if 'living' in its fullest sense is to be achieved. But there is the danger that too much emphasis could be placed on these difficulties, especially where employment is concerned, and therefore the potential of people with more severe disabilities may never be realised. Given the right



Public telephones. Dimensions suitable for wheelchair users circumstances, there are many demanding jobs which could be successfully filled by severely disabled people, allowing them to concentrate on their abilities, rather than their disabilities.

'It is important for architects to realise that people are different from each other, that wherever the line is drawn between physical normality and handicap there are people who are normal and people who are not.'

Architects by themselves cannot counteract the prejudices which hamper disabled people, especially in their search for work. But they can create environments in which such prejudices would not flourish. For example, there is the employer who would not mind taking on a disabled person, if the disability is not obvious, but who would draw the line at someone in a wheelchair, whatever their qualifications for the job, with the excuse: 'The steps would be difficult', or 'The wheelchair would take up a lot of space in the office.'



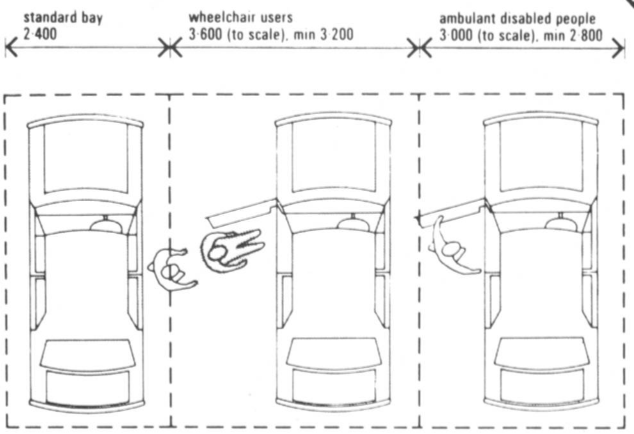
Space needed for standard wheelchair users to turn, for example, a corner in a corridor

Sometimes there may be valid reasons for this—if the office is up two flights of stairs, and there are no lifts, then employing someone in a wheelchair would be out of the question. But, says Selwyn Goldsmith,

'A determined disabled person, even if severely handicapped, is a very adaptable animal.'

'Encouraged by a reasonable and sympathetic employer they can fit into almost any situation, even though it might appear very unpromising at first.'

But to come up against a prejudiced employer can have damaging consequences to the confidence of a disabled person. One or two rebuffs, and it is easy to feel rejected, to feel that there really is no place for them in society. And this is an important reason why access, particularly in employment buildings should be as easy as possible. The simple business of social contact on an equal basis between able-bodied and disabled people helps to foster a more tolerant attitude towards disablement. The closer the social and personal contacts, the greater the acceptance of disabled people in general, and the greater the opportunities for them to become independent.



Preferred width of parking space for disabled drivers and passengers

Designs for new office and factory buildings, Selwyn Goldsmith says, should automatically provide for access by disabled people, and properly done this would mean that they should be able to use the buildings quite independently, without relying on help from other users. In large office buildings, for instance, it should be possible to cater for wheelchair users throughout, without conflicting with the overall design. Important points are: the approach should be accessible, with at least one entrance serving the reception area; all areas used by office staff must be accessible to people in wheelchairs; there should be proper toilet facilities for wheelchair users; and provision for disabled people not in wheelchairs, for instance support rails where needed.

In fact many of the basic principles laid down in his book make good design sense anyway, without the need to labour on their original purpose. Such things as accessible entrances, with an obvious reception point (do even able-bodied people have to climb those flights of steps, manoeuvre those heavy doors, and once inside, try to locate a reception area?). 'Prestige' buildings, whether a town hall or a head office, by their very insensitivity underline this perpetuation of 'apartness' or aloofness, and lack of feeling for the human scale. Most of the time people are unaware of the subtle way buildings shape their lives. They can make relationships between people and between their surroundings easy or difficult, and even determine, by their design, the pattern of the world around them.

Designing for the Disabled is a rarity—it encompases far more than its actual brief. It comments, it exhorts, and it explains. Its basis is humanity, for how society treats its disabled people is perhaps the ultimate test.

This article has been reproduced by courtesy of *Outlook*, The Rehabilitation and Resettlement Service Magazine, which is published by the Employment Service Agency. Marion Thomas is editor of *Outlook*. Diagrams are by Louis Dezart from *Designing for the Disabled,*

RESEARCH: Mrs Olwen Gibson, who has a degree in Maths and Education, is researching into the problems children with spina bifida and hydrocephalus encounter with number work at school.

She would be very pleased to hear from any primary school teachers who are particularly interested in this topic, and have experience of the problems.

Please contact her at: 705 Fulham Road, London SW6.

Pigeon racers cause quite a flutter

FOR THE sixth year proceeds from theRoyal Pigeon Racing Association Show are being given to ASBAH. We are enormously grateful for this substantial help—£21,500 to date, and we don't know yet what the proceeds from this year's Show will be.

This help is in addition to the "spin-off" which Local Associations have received from local clubs and shows.

I attended the show in Blackpool and it was a fascinating experience to be, for three days, in the company of so many pigeons and so many pigeon fanciers. The enthusiasm they showed rubbed off on me. I found I was talking to the birds too!

I am sure that advice and help would be freely available from the Royal Pigeon Racing Association if any readers wanted to take up this sport.

Joint action leads to major appeals

WITH the full approval and co-operation of the local Associations concerned ASBAH is launching two county Appeals this year, one in Buckinghamshire, and one in N. Hants, W. Sussex and S. Berks.

We also have a full time organiser—Rowland Lole—working in what used to be called Warwickshire and are planning a similar appointment in S. Wales.

We welcome this opportunity of working more closely together and if other local Associations would like to know more about these proposals I should be delighted to come and talk to Committees.

Home-based industry could be the answer

OVER the Christmas period we had so many examples of kindness and generosity and our annual appeal reached the record sum of £24,000. It would be impossible to tell you about them all, but one dear lady worked for a whole year making handicrafts and sent us the proceeds—£400.

This prompts the thought that this kind of occupation could be a source of income for those of our spina bifida members who are good at making things. Perhaps we could start a home-based industry? I'm sure there's a market for knitted woollen socks for one thing and all sorts of craft articles are now much sought after.

KATE WHITE

CLASSIFIED 'ADS'

THE CLASSIFIED advertising section is something new for LINK 'and we hope that your 'ads' will come pouring in!

It will take in 'ads' not only for Holiday Accommodation, but also articles For Sale or Wanted, For Hire etc. Let us know what you want to advertise and we will let you know if you can!

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

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

HOLIDAY ACCOMMODATION

Two bedroomed chalet, four-six berth, situated at **BASHLEY PARK** IN THE **New Forest.** Telephone: evenings only Portsmouth 68193.

CHRISTCHURCH: 6/8 berth Caravan. 1 mile from sea. Near New Forest. Club House. Mrs D. Collier, 2 Barnard Close, Nythe, Swindon.

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

MABLETHORPE: Two well-equipped chalets, self contained, 6-berth. Situated at Golden Sands Estates, Mablethorpe. Details: Mr B. Guest, 57 Bloxwich Lane, Walsall.

PRESTATYN: Two well-equipped 6-berth caravans. £25 (off peak £12.50). Mrs Taplin, Colonial House, 63 Corporation Street, Manchester M4 3DT.

SELSEY: Well-equipped specially designed, mobile home. 7-berth plus cot. Details (please send SAE) to: Mrs D. M. Driscoll, 26 Limes Avenue, Waddon, Croydon, CR0 4JX.

WESTGATE ON SEA: Semi-detached holiday bungalow, adapted for handicapped. Bath hoist. 10 mins walk sandy beaches. Garden. Sleeps 6/8. Details: David Randall 01-856 3436, 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.

WITHERNSEA: Well equipped 6 berth chalet at Golden Sands Chalet Park. Shop. Licensed club. Play areas. Amusements on site. Details send SAE to: Mrs P. O'Callaghan, 14 Dyer Lane, Wheatley, Halifax. Tel: 0422 56402.

FOR SALE

TEE SHIRTS: White Cotton with Green Family symbol and words Support Spina Bifida. £1.60 each 22"-30" £1.85 small, medium, large, plus postage. State size. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks, for Bucks/East Berks. ASBAH.

ASBAH booklets etc . . .

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

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

Scottish Spina Bifida Association Booklets

Growing Up with Spina Bifida, by O. R. Nettles, MCSP, ONC	20p

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

FUND RAISING AND PUBLICITY MATERIAL

Posters

Best Foot Forward 20 × 30 in.	**10p each**
Best Foot Forward 15 × 10 in.	**10 for 40p**
For local publicity 15 × 10 in.	**10 for 40p**
Car Stickers	5p each
Cards for Notice Boards	10 for 10p
Plastic Lapel Badges	3p each

All available from Appeals Dept.—postage extra.

The Appeals Dept. carries a range of fund-raising items, such as pens, balloons, calendars, matches, tabards, car stickers, etc. Send for full list and order form.

LINK: The deadline for material for May/June LINK is April 1. *Write to Mrs Susan Gearing, Editor, LINK, ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ.*

The yearly subscription for LINK (UK) is £1.15, which covers the cost of postage. Views expressed in LINK are not necessarily those of ASBAH. While every care is taken to ensure the accuracy of information published in LINK the publishers can accept no liability.

This article was originally a paper presented by Carole Sobkowiak last year at the Sheffield meeting of the Society for Research into Hydrocephalus and Spina Bifida.

The work described in this article represents part of a continuing research programme and further reports will be available.

Hand skills in children with spina bifida

NEATNESS and dexterity in movement is, in part, an inherited attribute and there is a wide variability in the population as a whole. Lack of motor skill occurs in about 5 per cent of school children, generally due to so called developmental dyspraxia, one of the causes of the 'clumsy child'.

There are several other causes of clumsiness many of which could be present in the child with spina bifida and we suspected that children with spina bifida were often less manually skillful or more frankly clumsy in hand usage than the normal child of the same age.

At the same time they are more dependent on their upper limbs because of a relatively manual existance, many spending much of their time in a wheelchair or using their hands for walking aids etc.

Any hand function difficulties must be recognised early and appropriate management instituted.

At the Sick Children's Hospital in Edinburgh we see most cases of spinal dysraphism occurring in South-East Scotland and during 1977 we investigated these problems in all of the six eight-year-old children attending the spina bifida clinics with the co-operation of their parents.

All children had firstly, a detailed neurological examination of their upper limbs and secondly, an assessment of hand function. This latter assessment was entirely of a practical nature and closely related to everyday activities the child would perform, such as fastening buttons, threading needles, catching balls, screwing lids on bottles, using scissors and many more. An example is seen in Fig 1.

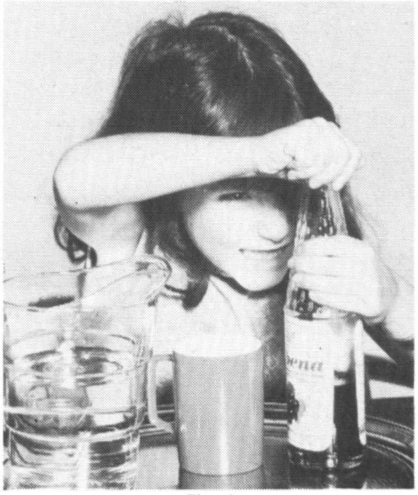


Fig. 1

In these tests we were concerned with *successful* accomplishment of a test and *not how* it was done.

Computer analysis of the results confirmed that spina bifida children showed considerable difficulties in hand skills compared to a group of children without spina bifida, in the same age range.

The neurological differences in the two groups of children were of two main types. There was significant delay in neurological maturation in the spina bifida group. The second difference concerned muscle power and co-ordination in the upper limbs. Only 29% of spina bifida children had maximum scores for muscle power in their upper limbs and in particular the more distal muscles were weaker. These latter signs are doubtless a result of cerebral ventricular distension.

The functional differences between the two groups of children were striking, the spina bifida group being well below their normal peers and not showing the improvement with age that occurs normally.

Moreover children with a problem with their hands were identified who may not have been suspected on formal neurological examination or usual psychological testing.

The factor which seem to be most closely related to difficulties in hand manipulation appears to be the presence of hydrocephalus with or without the need for a shunt. It is possible that the actual congenital abnormality of the brain (Arnold Chiari malformation) which causes the hydrocephalus could in itself cause difficulties in co-ordination. Hydrocephalus is especially likely to cause damage to the pathways which convey voluntary skills in these children.

In our study we found several spina bifida children who are of normal intelligence, at normal schools and walk normally — such as the child in Fig 2 — with excessive laxity about his upper limb joints who had a hand function score of only one quarter of that expected.

Recognition and understanding of a problem is the first principle in management. Unconventional 'trick' movements, by-passing difficulties, developed by the child himself are often highly skilled in themselves and are not to be discouraged. On the other hand dogged determination and regular practising of conventional movements may prove less efficient and the child may become discouraged and frustrated.

Specific treatment should be individualised. A group of spina bifida children will benefit from an intervention programme with physiotherapists but almost all will benefit from gross movement therapy in the form of regular and competitive swimming, remedial gymnastics etc.

A further group with dyspraxic features will need special consideration, with aids provided by occupational therapists, such as velcro straps instead of buttons on jerseys and trousers, slip-on shoes without laces, typewriters and tape recorders etc.

Handicapped children generally may have difficulties sometimes which are not always obvious and this study highlights the need for continuing research. We are grateful to Action for The Crippled Child for support.

J. K. Brown, Consultant Paediatric Neurologist
R. A. Minns, Research Fellow
C. A. Sobkowiak, Superintendent Physiotherapist
ROYAL HOSPITAL FOR SICK CHILDREN, EDINBURGH

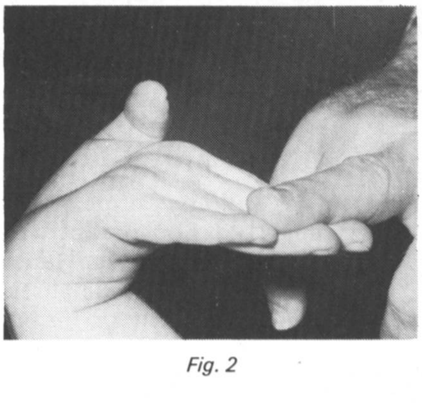


Fig. 2