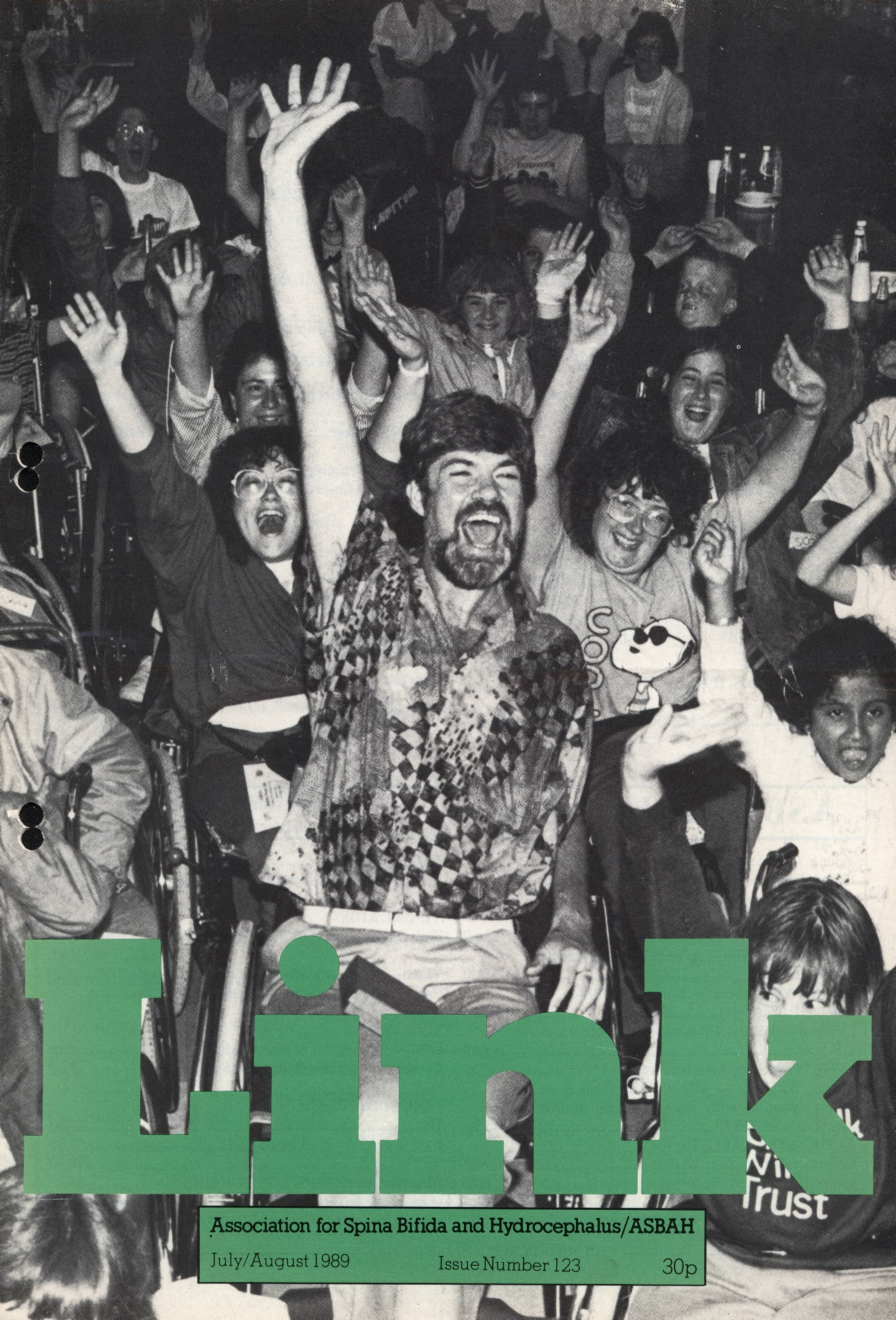

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Association for Spina Bifida and Hydrocephalus/ASBAH

July/August 1989 Issue Number 123 30p

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Cover - Matthew Kelly and participants at Mobility Week.

contents

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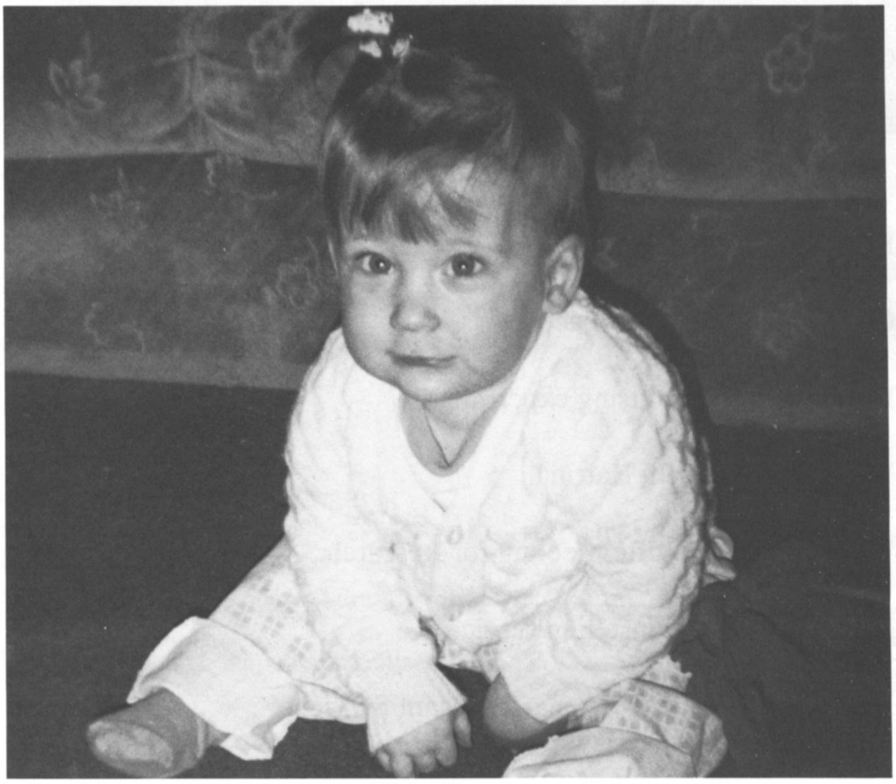
Baby Roxanne

"I know the feelings of being alone when your baby is diagnosed as having a disability, but no matter how bad things seem or actually get, there is light at the end of the tunnel".

By Divinia Regan

On the 13th February 1988 at 3.37 a.m. we had a beautiful baby girl. I will never forget that feeling - it was as if a wave of warm air rushed over me. Roxanne was instantly precious to us. But I instinctively knew that everything was not right as I could not stop bleeding.



Roxanne at 13 months.

The paediatrician told me Roxanne had spina bifida. I immediately thought how glad I was that she was alive and when the baby was handed to me, I was scared I would hurt her. They sealed her back on the same day - she was not even 12 hours old. I phoned my parents in tears. I was allowed to see her at 2pm when she was back from surgery but I did not hold her that first time - she was so small and dainty. I was in awe of her.

In the post-natal ward one mum was crying because her daughter was suffering from jaundice. I then realised that, like me, the other mums were worried about their babies. We all agreed that if we were to cope we had to accept things as they were. There was no use leaving the blame at anyone's door; it wasn't going to change Roxanne's problems. She was meant to be special.

Baby Roxanne, at 3 months, with parents Divinia and Paddy Regan.

Later on in the first week my husband Paddy and I were shown to a room where a doctor was waiting, and there the bombshell was dropped - Roxy might develop hydrocephalus. We were in tears.

Roxanne was transferred to a children's ward for a week, then came home on Paddy's birthday. It was chaos for about a week until we got organised. We were exhausted and I cried now and then because I felt so inadequate, but Paddy was a great help - he was always there when I needed a shoulder to cry on. Coping has drawn us closer together. The rest of the family were great too, supporting us when we needed it.

Roxanne started physiotherapy at 5 weeks old and she now crawls around. I found it difficult to stop being overprotective, but I knew in the long run it was in her best interests to let her sit on the floor unsupported.

We even got permission to take her to Ireland for 10 days to see her other grandparents.

A couple of days after we returned, Roxy had her shunt fitted and the operation went well. The sister on the ward handed Roxy to me as I was too scared to pick her up. I held her so stiffly that I suffered with cramps in my arms for the rest of the day.

Ten days later Roxy came home. There was a softness in her eyes that we had not seen before. She progressed well until late August when she started having urine infections. I learnt to catheterize Roxy, which I did three times daily, but when the infection continued she had another scan which revealed a reflux in her left kidney. By December I was at my wits end when she fell ill again, but this time it was different because she was sleeping all the time. The doctor gave us some antibiotics to try her on.

By December 12th I was worried sick. The consultant I saw was unimpressed and said that Roxy was fine. By the 14th I was hitting my head against a brick wall and was beginning to think that I was the paranoid mum that the unfeeling doctor passed me off as. As luck would have it I was due to take Roxanne to see the urologist and he asked why I was not catheterising Roxy 6-7 times daily. I had lost count of the number of time I had asked people about this. Everyone had said 3 times daily was ample. The urologist asked me to bring Roxanne back in 8 weeks which felt like an eternity. I could not hold myself back any more, I burst into tears saying that I could not take her home in the state she was in. I wanted her examined thoroughly and I jumped at the doctor's offer to hospitalize her for 2-3 days.

Exploratory surgery was not conclusive although they thought that the shunt was the problem. She was in at 9pm and was not back at midnight. Paddy and I did a lot of soul searching. We both prayed to God she would be alright. I still thank Him for the precious gift he gave us.

She was a little better by Christmas Eve but she wasn't the Roxy we knew. The shunt was re-sited and at 5.30 a.m. on Christmas Day we were telephoned from the hospital to consent to having an external drain fitted because of the infection.

It tore my heart out when she came back sobbing with pain. I could feel the pain too, but mine was emotional pain.

On January 22nd we were finally given the "all clear" to bring Roxy home. Since she's been home she has been up to all sorts. It has been the longest time we've had together as a family - and that's how we feel. She is just so cuddly and loving, we wonder what on earth we did to deserve such a wonderful little girl.

> ***"We agreed that if we were to cope we had to accept things as they were. There was no use leaving the blame at anyone's door."***

During all this I did my homework by asking questions, reading books and listening to doctors. I now know quite a lot about spina bifida. I have learnt never to feel embarrassed to ask if I don't understand. I don't feel inadequate any more. I pushed for much of what we received and I no longer feel guilty about asking for help when we need it.

Now things are on an upward climb and we take things day by day. To look at Roxanne now you would think shewas an average 15 month old baby. She is doing all that she should, but a little later. She makes me so humble; she is wonderful.

At 9 months, doing some physiotherapy with Mum.

Christine goes to the Palace.

Looking lovely in a royal blue and white dress, Christine Helliwell of Brighouse, West Yorkshire, pushed her wheelchair out of the Buckingham Palace grounds, where she had just attended a Royal Garden Party on 11th. July.

Christine Helliwell

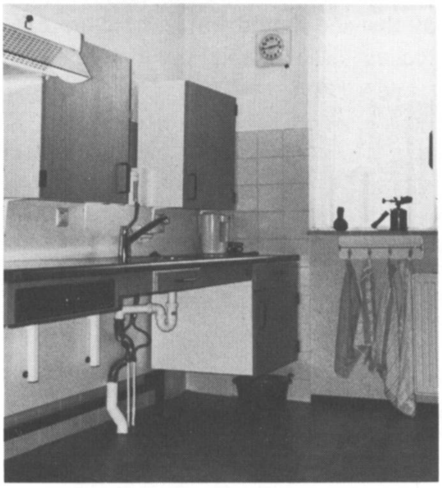
Christine, a 41 year old analytical chemist with spina bifida, explained proudly that her invitation was due to having "achieved a lot as a disabled person in society". "When I was younger", Christine explained, "the prevailing attitude was that disabled people could not be educated". At that time Christine received a total of 2 hours of education per week. But, due to Christine's own determination and her parents' desire for her independence, Christine completed her education and worked hard for an Open University degree in sciences, awarded in 1986. Christine lives independently in her own home and has had a very active role in her community as a Brownie Leader and Sunday School teacher, in addition to her full-time occupation.

Christine is also writing a book of her life-story because she feels so strongly about encouraging the independence of disabled people.

"Housing for all."

Carolyn Smith, previously ASBAH's Accomodation Officer, reports on an encouraging Dutch experiment that successfully addresses the challenge of "housing for everyone".

I attended a seminar called "Building Adaptable Housing" held from May 31st to June 2nd 1989, in Nunspat, Holland, as representative of the International Federation for Hydrocephalus and Spina Bifida (IFHSB), The seminar and demonstration of this experiment in flexible, comfortable and cost efficient housing is hoped to provide a model for future housing policy throughout Europe.



A block of adapted flats (top) and an adapted kitchen.

The seminar was an initiative of the Nationale Woningraad (NWR), an umbrella organisation for housing corporations in Holland, working in conjunction with the commission for the European Community. The seminar aimed to inform member states of the European Community of the Dutch experiment of Adaptable Construction which commenced in 1985.

Participants from 14 nations were invited, most of whom were architects and housing professionals. Disability groups were somewhat under-represented, reflecting the decision-making power of the housing providers.

The NWR define "adaptable housing" in the following way: "Building adaptable housing is the creation or renovation of accommodation which is not specifically adapted and intended for disabled occupants but which is designed in such a way that it can be adapted easily and relatively cheaply should an occupant become disabled at some future stage in his or her life". This definition highlights a number of important ideas. Firstly, it emphasizes that adaptable houses are not houses for disabled people, but homes designed to be easily adapted if required. This "dynamic strategy" ensures that all housing meets basic requirements which allow for adaptation to suit a disabled occupant. Consequently, a person would not be compelled to move out of their home should they become disabled, nor does it force people to remain in hospital or residential care because of a lack of suitable housing.

Adaptable houses increase the likelihood of social integration for disabled occupants by widening their choice of housing options and improving access to neighbours' homes.

The adaptations to such homes can be as easily reconverted later. Thus, the families of disabled residents would not be compelled to leave an adapted property once the disabled person leaves or dies.

Secondly, the ease with which such homes can be adapted makes the alterations comparatively fast and inexpensive. The experiment demonstrated that adaptable housing reduced the cost of later conversion by 70-90% in comparison to the cost of non-adaptable home conversion.

The NWR experiment had to consider design specifications and cost in order to gain the acceptance of other housing providers. Consequently, architectural objectives and conditions for adaptable housing were specified in the publication, "Requirements for Adaptive Housing". These building criteria have already been successfully used in 20 of the projects completed. Working to these criteria, the NWR discovered that constructing adaptable housing was similar in cost to non-adaptable housing.

In addition to the discussion, the seminar's participants visited Winterswijk, a small Dutch town close to the German border, where two adaptable housing experiments were conducted.

One project comprised of three-storey block of flats accessed by a lift. Each flat appeared quite ordinary in the absence of any "special" design features, and the internal wall could be relocated or removed if required, creating an atmosphere of spaciousness.

One of the flats was adapted to accommodate a wheelchair. The adaptation, apparently effortless, consisted of installing a height-adjustable kitchen unit. Otherwise, the flat was no different from the other houses in the block.

The seminar participants were unanimously in favour of adaptable housing as a result of the seminar and demonstration and were impressed by the enthusiasm of the Dutch architects, who are so eager to see other nations adopt this approach to housing. The participants agreed upon three main recommendations:

- That the conference required follow-up from the NWR which would include workshops to discuss implementations of such a programme on a European scale within a specified time span.

An adapted kitchen, demonstrated by the tenant.

- That this dynamic strategy must be customer-orientated, requiring further investigation in itself.

- That adaptable housing should be viewed as a temporary step working towards the ideal of "housing for everyone".

The successful Dutch experiment in Adaptable Housing has demonstrated a nation's commitment to providing a housing policy which meets the needs of its entire population, disabled people included. This commitment has, to date, not been found amongst other housing providers in the United Kingdom, or indeed in other European countries. The seminar will hopefully be the first of a programme of discussions about adaptable housing which will lead to European policy guidelines and directives.

Wing-walking with Katrina

31 YEAR old Katrina Hocking from Witney, near Oxford, requires the use of a wheelchair for shopping trips but enjoys wing-walking on aeroplanes for relaxation.

Born with spina bifida, no knees and having developed rheumatism, osteoarthritis and muscular dystrophy, Katrina enjoys nothing more than being strapped onto the wings of a planeand remaining there for a flight. "Thrill-seeking runs in my family", she explains.

In 1987 Katrina was one of nine to be granted a scholarship to gain a pilot's licence. During the day she works as a civilian clerk at Brize Norton Air Base. At weekends she enjoys sponsored fundraising for Great Ormond Street Hospital, under whose care she spent five years. "I have just completed a Triple Challenge which included abseiling and an air-sea rescue as well as wing-walking" she explains.

Her ambition, though, is to help other disabled people gain a pilot's licence. "The freedom of flying is brilliant. When I am in the cockpit of a plane I am the same as everybody else. It is society at large who determines the range of experiences considered appropriate for people with disabilities - my message is get out there and achieve", she laughs, with a twinkle in her eye.

"You might meet some resistance along the way; all my friends think I am crazy", she quickly adds.

Fear is a word which does not easily creep into Katrina's vocabulary. Her other ambition is to take up rally driving. "I have driven a car for 13 years and enjoy the sensation of being at one with a vehicle" she insists.

"I won't say that I am never scared, but I do enjoy adventures and I try to maintain enthusiasm whatever obstacles I might have to overcome on the way to my goal."

Katrina Hocking, the "wing-walking" pilot.

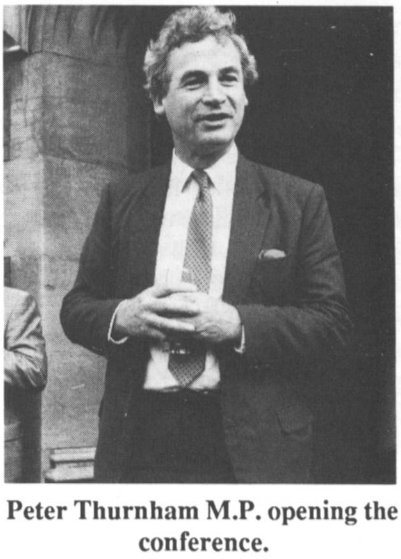
The Thirty-Third Scientific Meeting of the Society for Research into Hydrocephalus and Spina Bifida.

The President of the society Miss Moyna P. Gilbertson, with three past Presidents. Mr Duncan Forrest, Prof. Laurence and Prof. Anderson.

The 33rd Scientific Meeting of the Society for Research into Hydrocephalus and Spina Bifida was held at St John's College, Cambridge on 12 - 15 July 1989.

It was the largest meeting the Society has so far held and emphasised its multi-disciplinary character. The meeting was opened by Peter Thurnham, Member of Parliament for Bolton East, who has shown a great interest in all aspects of disability for many years and has been an enthusiastic supporter of organizations dedicated to research.

Whilst delegates enjoyed a scientific programme of a very high standard, accompanying persons were able to explore Cambridge and the surrounding countryside. All of the delegates visited Ely Cathedral and Wimpole Hall and had a reception and dinner at Queens' College.



Peter Thurnham M.P. opening the conference.

The delegates at the meeting.

From near and far. Dr. Malcolm Menelaus from Australia and Dr. Gillian Hunt from Cambridge.

Miss Moyna P. Gilbertson, Dr. Clarence Greene, Dr Lynn Goodoe-Greene, Mr Kimberley Greene, Mr Clarence Greene and Prof. Keasley Welch.

The Society dinner in St John's Hall gave everyone an opportunity for relaxed conversation and to make plans to meet again, and to enjoy the excellent singing of the Gentlemen of St John's.

The meeting gave a number of ASBAH staff the opportunity to meet members of the Research Society and we look forward to closer contact in the future.

Moyna P. Gilbertson with Prof. and Mrs. Lachmann.

ASBAH's

New Counsellors and Workshops.

The appointment of two senior counsellors to ASBAH's Fieldwork team has paved the way for a series of workshops. Here, in the first of two articles, we explore how these special days will help parents understand and support their offspring as they make the step into adulthood.

For most young people the transition from childhood through puberty into adulthood is a difficult time. For young people with spina bifida and/or hydrocephalus the problems are more complex. Restricted physical mobility and dependence on others to help with daily tasks leaves little space for self-exploration and development.

On 1st July the first of a series of Counselling Workshops took place in Reading, to help parents cope with the teenage years. Parents brought to the Workshop some of their questions, fears and problems relating to the development of their young offspring. For far too long there has been a taboo about relationships and sexuality in relation to people with spina bifida and/or hydrocephalus, and ASBAH strongly feels that this whole area has got to be addressed.

> ***"The Workshops spearhead a new counselling service ASBAH is offering to families, which is in direct response to parents' expressed need."***

The Workshops are run by two experienced Counsellors. Pat Edser, who not only has four years' experience with ASBAH as a Fieldworker but is a specialist in sexual problems, and Kath Pickin who is a trained Marriage Guidance Counsellor and at present is based at Five Oaks, as a Nursing Advisor.

The Workshops spearhead a new counselling service ASBAH is offering to families, which is in direct response to parents' expressed need.

A small team of Counsellors led by Pat and Kath have been appointed. They are committed to offering an on-going support service to parents, as well as young people, in both group settings and on a one-to-one basis. The Workshops act as catalysts, and will be followed up by counselling to offer support to individuals and their families.

Pat and Kath are quick not to apportion blame for the young people's late emotional development. "Teachers, carers, doctors and parents all find it difficult to allow young people privacy, or indeed an opportunity to indulge in teenage experimentation. Part of the problem is due to lack of mobility which leads to reliance on adults instead of peer company."

Kath is convinced that in order to help parents give their children the blessing to move forward emotionally into adulthood, they have to look at their own feelings. "There are a lot of deep feelings associated with giving birth to a disabled child, which in most cases have never been addressed. Having missed out on early emotional support, the realization that their children need to mature into adults is often a difficult step for parents to take."

It is hoped that, through the workshops, parents will become more aware of the problems faced by young people and that they will feel more confident and able to discuss subjects like relationships and emerging sexuality.

Kath finds it surprising that few families have discussed the disability of their child with its brothers and sisters. "A lot of pressure can be placed on an able-bodied sibling who is expected to compensate for the disabled member of the family."

"Other children in the household are often asked blindly to love and cherish their disabled sister or brother, instead of realizing that they will, quite normally, run the gamut of brother and sister feelings. These can range from jealousy and resentment right through to pity and love."

Without good communication marriages can split up, brothers and sisters can become emotionally damaged, and the disabled person can start to display inappropriate behaviour.

> ***"Other children in the household are often asked blindly to love and cherish their disabled sister or brother, instead of realizing that they will, quite normally, run the gamut of brother and sister feelings."***

Unacceptable social behaviour can range from barging in on a conversation, to constantly touching someone. Pat illustrates this through an experience of a 25 year old young man who was particularly lonely. "One day he wheeled himself into his local pub and went up to a couple who were sitting at a table and just started talking to them. They got up and left. He was terribly hurt because he felt that they were discriminating against his disability. In fact they had been engaged in a private conversation and felt intruded upon."

Pat believes that through counselling, or good family interaction, incidents need to be explored and lessons learnt. Childlike behaviour is often excused, temper tantrums dismissed, and the young person is often shielded or over-protected. It is often painful but necessary to explore the deep insecurity which lies beneath an incident. Kath knows one couple who prefer to cuddle in public, rather than in the privacy of their own flat. She puts this down to their anxiety about being alone.

It is the inner pain, disappointment and confusion faced by young people with spina bifida and/or hydrocephalus when their expectations do not keep up with their emotional development, that parents need help in acknowledging and addressing.

It is difficult to instil modesty and dignity when constant medical examination, hospitalization and incontinence problems have allowed carers to intrude on human privacy. The realization for parents that their offspring are sexually aware and need the physical reassurance and affection which all adults crave, can be hard. Society has placed an almost crude interpretation on the word 'sex', instead of exploring the emotional satisfaction which can be gleaned from a close physical relationship.

The formation of friendships, and the ability to sustain and build on a relationship can have disappointing results. It is not uncommon for a young person to imagine that two meetings equals an engagement. It is impossible to know whether this is due to wishful thinking, a deep need to mimic what is considered to be adult behaviour, or a lack of understanding through inexperience.

Parents often have questions as to whether their children will be able to reproduce. If a young person wishes to find out, medical tests can often provide answers. Many women with spina bifida have given birth to healthy children, whilst some men can father children. However, medical exploration means emotional preparation and support, if answers are not favourable.

It is hoped that ASBAH's counselling service will offer parents an opportunity to explore their own feelings and gain the confidence to help their children through the teen years. It is only if young people with spina bifida and/or hydrocephalus are given an opportunity to make decisions, and mistakes, that they will start to mature. They need information and, more important, time to reflect and time to move forward.

ASBAH plans to hold workshops exclusively for young people later in the year.

Personal Assistant Services.

"A human and civil right."

The first initiative by disabled people to develop a European policy on Personal Assistant Services took place in the European Parliament in the spring. This initiative to help people with disabilities live independently in the community came before the Government's response to the Sir Roy Griffiths' Report "Community Care - Agenda for Action".

> ***"Personal assistance services are a human and civil right which must be freely available, to all disabled people. Wheelchair users should be able to choose from various modes with different degrees of user control."***

Health Secretary, Mr. Kenneth Clarke, has proposed radical plans which would give more support to people in their own homes. Local authorities will be responsible for budgets and designing tailor-made arrangements according to each person's needs. A White Paper will be published in the autumn will be put into action in 1991.

70 disabled people from 14 European countries attended the personal assistant seminar in Strasbourg and 11 resolutions were drawn up and will be presented to Governments and policy makers. It was felt that personal assistance services are a human and civil right which must be freely available to all disabled people. Wheelchair users should be able to choose from various modes with different degrees of user control. There should be adequate services so that disabled people can take on the responsibility of work, leisure, travel and family life. Services should be availabe for 24 hours every day. The funding authority must ensure that money is available to the user for adequate support, counselling and training. Funding must cover competitive wages for the assistant and appropriate benefits. Funding should be a legislative right with payment guaranteed. The user should be free to choose and appoint the Personal Assistant, including a family member if they so wish. No person should be placed in a residential setting for want of resources or services.

> ***"There should be adequate services so that disabled people can take on the responsibility of work, leisure, travel and family life. Services should be availabe 24 hours a day every day."***

There should be a uniform judicial appeals procedure independent of funders, providers and assessors, and legal aid. Disabled people or their organizations should be involved in planning and implementation.

Mastering the back wheel balance at Mobility Week.

TV personality Matthew Kelly was the special guest and prize-giver at the Ludwig Guttman Sports Centre, Stoke Mandeville Complex on 7 July for ASBAH's successful Mobility Week. It was attended by 87 children between 10 and16 years of age from throughout the U.K.

The focus of the week, mobility and thus self-development, was reflected by a range of challenging activities. These included basketball, swimming, wheelchair manoeuvres, and a number of lectures and discussions on important topics such as incontinence, diet, sexuality and spina bifida itself.

It is the first time that such a week has been conducted by ASBAH. Phill Watson, the manager who organised the Mobility Week, explained that the acquisition of important mobility skills such as the back wheel balance is fundamental to independent living and thus to the overall personal development of the wheelchair user.

Back wheel balancing is simply the ability to tip a wheelchair backwards in a controlled manner so that the front wheels are raised from the ground. When first attempted it can be frightening, as it feels that you will tip over completely. However, all wheelchairs have a balance point which, when reached, can be held easily. Once this stability is held it is possible to move on only the back wheels.

> ***"he focus of the week, mobility and thus self-development, was reflected by a range of challenging activities."***

The first advantage of mastering the back wheel balance is the ability to mount kerbs, with obvious implications for mobility and independence. Phill estimates that of the 87, half could do this before the course and, of the other half, the vast majority learned this for the first time during the week.

Phill believes that lack of independence is often linked to lack of confidence which means that a person does not reach their full potential. Mastery of the back wheel balance has, hopefully, enhanced the participants' confidence to attempt other new challenges which will carry over into many aspects of their lives. Ian Laker, John Naude and Jamie Gilham who, as well as working at ASBAH, are disabled, offered the young people a good model of what can be achieved in life.

These emotional and psychological aspects of development in the young disabled person are viewed as equally important as the physical - this Mobility Week also focused on knowledge, attitude and the psyche. While it is difficult to measure the extent of these changes, Phill and others were encouraged by the amount of learning that seemed to take place. The learning process is, however, a gradual one, but it began by raising questions of "who am I?" and "what am I doing?"

The success of the Mobility Week will depend upon the parents and carers of the participants, whom Phill hopes will be able to reinforce the new skills and foster the development of the young person. This can be difficult to achieve in another enviroment "The parents or carers may face some difficulties coping with the

Matthew Kelly with a group of participants during Mobility Week.

Matthew Kelly presenting a prize to John McElhatton

challenges of their developing child or accepting and allowing their child to become more independent" Phill explained. "We view the needs of parents and carers as being just as important as those of the disabled person themsleves". ASBAH's counselling service could be of assistance to carers who face such problems.

> *"The success of the Mobility Week will depend upon the parents and carers of the participants, whom Phill hopes will be able to reinforce the new skills and foster the development of the young person."*

The organisers acknowledge that, being the first of its type, the week was a learning experience for themselves as well. There will be a thorough analysis of the week, but all agreed that something similar must take place in the future. Many friendships were formed during the week and, despite the challenging tasks and distance from home, "none of the participants seemed really unhappy" says Phill.

The participants themselves responded positively to Mobility Week. Lisa McBeth, 15, of Abingdon, Oxfordshire said she can now relate better to other young people through the friendships she formed. "I thought I knew a lot about spina bifida", Lisa adds, "but I have now learned a lot more about my own disability". She found moving backwards in the wheelchair difficult, but swimming easy. Lisa concluded, "I would recommend it to anyone". John McElhatton, 15, of Cookstown in Northern Ireland, similarly found some wheelchair manoeuvres difficult, but nevertheless enjoyed everything about the Mobility Week. Chloe Mears, 10, of London, said that although she "missed Mummy a lot" she enjoyed Mobility Week and would come again next year. Everyone enjoyed the disco that ended the week and many lucky participants won prizes, in addition to getting Matthew Kelly's autograph.

Matthew Kelly and all the people who attended the week.

Tougher Charity Laws.

Charities are in the news again - this time on two fronts. First, the recently published Harvest Charities Report has announced that charities are currently raising an estimated £15 billion per year - roughly 3% of the gross national product.

Yet, according to the report, British people are fairly mean in their donations to charity. We only donate 0.85% of our household incomes to charity whereas, by comparison, the Americans donate more than 2%. Much of this apparent meanness is because the majority of British people believe that the responsibility to take care of people who are unable to take care of themselves belongs with the Government.

Nevertheless, charities are increasingly expected to take on more responsibility for providing welfare services, and there is no doubt that they are in a position to meet social demands in much more flexible ways than either central or local Government agencies.

Over and above the £15 billion, the Harvest Charities Report suggests that there is still great potential for charities to raise yet more money. Certainly the success of Band Aid and Live Aid indicate that strong publicity, 'star' support and short-burst fund-raising activities have the required impact, especially among the younger generation.

The second piece of news is rather more serious. A recent Government White Paper has announced the intention to curb some of the more dubious of fund-raising activities and the operation of charities in general. In particular the Government is keen to stop three types of abuse:

- The excessive sums retained by some fund-raisers;
- claims that part of the proceeds from the sale of goods or services will go to charity when, in reality, the share actually given to the charity is smaller than advertised.
- fund-raising activities carried on in a charity's name but without its knowledge or approval.

The White Paper outlines various provisions designed to combat the above and largely follows the recommendations put forward as a result of the inquiry by Sir Philip Woodfield in 1987

> ***"The success of Band Aid and Live Aid indicate that strong publicity, 'star' support and short-burst fund-raising activities have the required impact."***

Charities will have to contribute towards the extra costs created by the provisions via a flat-rate registration fee of £25. Anyone engaged in fund raising on a charity's behalf will have first to obtain its written permission, and house-to-house collections without local authority permission will be made an offence. There will also be a requirement that those receiving funds for or on behalf of a charity should remit the full amount to it, without deducting any fees or expenses. These can be remitted later. Charity catalogues will be required to include a statement showing what percentage of net or gross profits or monies received will go to a named charity.

Other provisions are similarly designed to curb dubious activities whilst at the same time protecting the reputation of reputable organisations.

For example;

- a requirement for all registered charities to submit accounts and other information annually to the Charity Commissioners;
- the exclusion from trusteeship of anyone convicted of offences involving fraud or dishonesty;
- giving Charity Commissioners a discretion to require a charity to have at least three trustees;
- measures to ensure that the register of charities is accurate and up to date;
- a widening and simplification of the Charities Act 1985 to allow more small charities to change their objectives, amalgamate or wind up;
- reform of the law on public collections and measures to deal with unscrupulous professional fund-raisers;
- powers in certain circumstances for the Charity Commissioners to appoint receivers and managers and to transfer a charity's assets to another charity.

Despite all these measures, and a searching look at the operations of charities, the Government has refused to amend the law relating to the definition of charity status, on the grounds that to do so would create anomalies. This leaves the grey area the question of whether religious cults should enjoy charitable status, principally because Home Office officials are concerned that any change would adversely affect reputable religious charities.

Even so, the proposals put forward in the White Paper will go a long way towards curbing disreputable practices and enhancing public confidence in charity fund-raising.

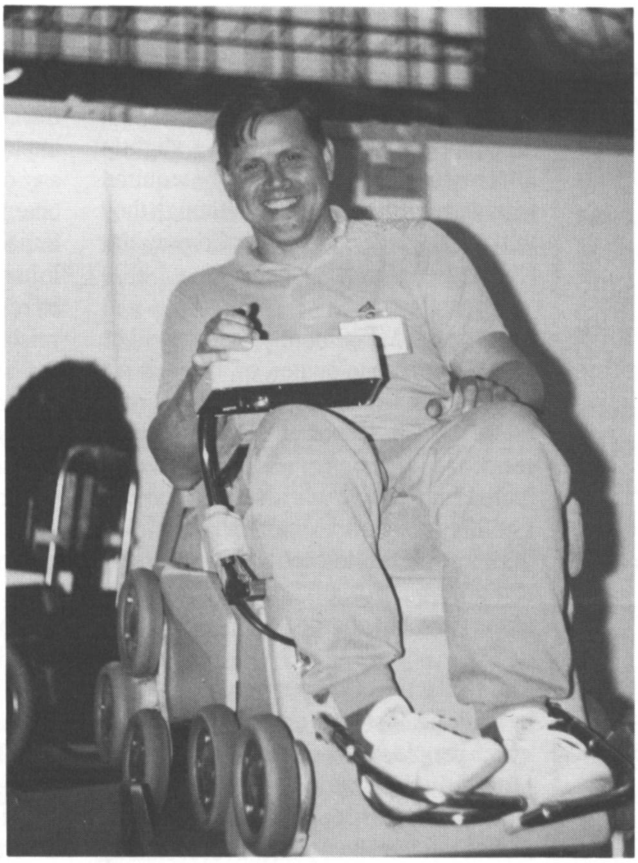
Getting a lift from Naidex.

Over 200 companies were on display at the Northern Naidex which took place in Manchester in May.

Naidex is 15 years old and has certainly become a firmly established event, although this was only the second time that the exhibition has been staged at a northern venue. There was a sense of hard selling techniques amongst the leading manufacturers on hand to offer advice to the elderly and those with disabilities.

Nevertheless, such an occasion did offer the opportunity to assess a wide range of products under one roof.

A new transfer board, simple in design, has come onto the market thanks to Pear Associates. Lifting and moving someone who is disabled can be difficult and strenuous and even dangerous if not done properly. Pear Associates have spent three years discussing everyday handling problems with carers, physio and occupational therapists. The transfer board can be used with or without assistance and is shaped to bridge even the most awkward gaps especially those between the wheelchair and car or toilet and between chairs with arms. There is also a belt which can be used in conjunction with the board or to assist with unavoidable manual transfers.



The Mobility 200 powered wheelchair.

The Onward patient transfer system.

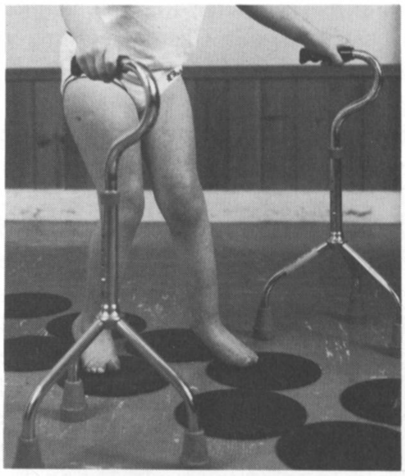
The transfer board costs £30 and the belt £5 inclusive of VAT from Pear Associates Ltd, 1 Roko House, Bridge Street, Derby DE1 3LB.

Not a new product but a useful one in the home or for those with disabilities is Dycem non-slip. This is manufactured from a specially developed PVC compound. It comes in a range of shapes from strips to mats. It holds objects in place without permanent fixing. It can provide an improved grip on handles, lids, tools and armrests. During physiotherapy it has been used to provide stability and security.

Prices start at £1.70 plus postage and packing for strips. For full details and stockists contact Dycem Ltd, Ashley Hill Trading Estate, Bristol BS2 9XS.

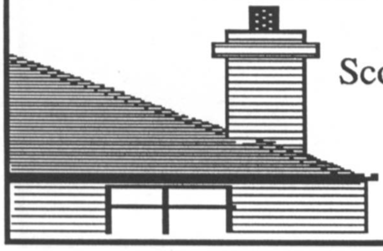
The Mobility 200 powered wheelchair at £3,900 is very much the other end of the price-range. Education Departments and the Manpower Services Commission have been known to purchase them for those at school or in employment. "It is not suitable for everyone" explains Mike Wood who helped design the chair following a spinal injury. "You have to have a very clear mind". Mobility 200 can walk over soft and uneven ground as well as climb steps and curbs. Mike Wood is always pleased to demonstrate the wheelchair.

He can be contacted at Mobility 200 (Telford) Ltd, Telford Industrial Centre, Stafford Park 4, Telford, Shropshire TF3 3BA.



Dycem pads being used for physio.

The Community Charge



Scotland already has it - England and Wales will soon have to face it!

There has been a lot of debate, opposition, even suggestions of downright refusal to co-operate with the charge. But what is the Community Charge - more popularly known as the "Poll Tax" - all about?

The Local Government Finance Act 1988 contained a number of provisions to revamp the present system by which local government is financed. The most important of these provisions was to remove the old domestic rates system and replace it with a locally determined flat rate community charge. The intention was that this should be paid by almost all adults living in a particular local authority area. So, whereas a rate demand is usually sent to the 'head of the household', now all adults (ie. those over the age of 18) will each receive separate community charge bills.

The charge actually takes three forms:

- Personal Community Charge
- Standard Community Charge
- Collective Community Charge

One or other of these types of charge will be made against all adults, unless they are exempt and registers will be maintained by local Community Charge Registration Officers.

The Personal Community Charge will be levied against any person aged 18 or over who is solely or mainly resident in the area of a charging authority. Married couples - or those cohabiting - will be jointly and severally liable. This means that though each is billed separately, if one defaults, the other partner will have to pay both bills. It should be noted though that this does not apply to parents whose adult children default. They will not be held responsible for their childrens' bills, since the "children" themselves will face any ensuing penalty.

Students will be dealt with on a slightly different basis. They will only be required to pay one fifth of their bill, although they will not be entitled to claim Community Charge Benefit.

The Standard Community Charge will be levied against the owner, or, if let on a 6 month plus lease, the leaseholder, of a house which is not the sole or main residence of any person. This would include any people with a second home or a holiday home for example. The amount of charge will be decided by each charging authority, but will be based on a percentage of the personal charge.

The Collective Community Charge will be made against landlords of properties in which people stay - as their main residence - for fairly short periods. In these cases it would be particularly difficult for authorities to collect personal community charges, therefore, the collective charge will be billed to the landlord, but residents will be expected to pay contributions towards this at a daily rate.

> ***"Married couples - or those cohabiting - will be jointly and severally liable. This means that though each is billed separately, if one defaults, the other partner will be have to pay both bills. This does not apply to parents whose adult children default."***

The landlord will have to keep records of short stay residents showing both the length of time they stayed and the amount of contributions they made towards the total collective charge. She or he will be allowed to retain 5% of the total as a collection fee.

Exemptions from the Charge:

Certain categories of people will not have to pay the personal community charge or any contributions towards the collective charge. These are the severely mentally impaired; those solely or mainly resident in hospitals; those solely or mainly resident in residential care homes; those serving prison sentences or held on remand; those for whom Child Benefit is payable (ie under 19 and still at school); volunteer care workers; the homeless; members of religious communities who are wholly supported by the communities; diplomats and members of international headquarters; and visiting servicemen.

To be classed as "severely mentally impaired" the person must be entitled to Invalidity Pension or Severe Disablement Allowance, or have reached pensionable age. The person will normally be suffering from a state of arrested or incomplete development of mind which involves severe impairment of intelligence or social functioning, or an injury to the brain causing severe impairment of intelligence or social functioning and which appears to be permanent. It will also be necessary to provide a GP's certificate stating that the person is severely mentally impaired.

Everything is calculated on a daily basis so someone may be exempt one day, but not the next and it will be each individuals responsibility to advise the Community Charge Registration Officer of any relevant change in their circumstances.

People with physical disabilities are not exempt from the charge. This is because it is assumed that they - unlike those with severe mental impairments - will be able to vote in local or general elections and should therefore be subjected to the charge. However, they may be able to take advantage of Community Charge Benefits on grounds of low income.

or "Poll Tax" replaces the rates in 1990.

By Linda Avery

The new rebate system:

The new rebate system will be called Community Charge Benefit (CCB) and may be available to people on low incomes who are liable either for the personal community charge or for their contribution towards a landlords collective charge, or for students who will already only be required to pay 20% of their liability.

CCB can be claimed anytime during the thirteen weeks prior to the date when the person believes she or he will become entitled to the benefit, or if they believe there is likely to be a change in their circumstances. Normally the benefit has to be claimed in order for the claiment to be considered for the CCB. However, where people are already claiming Housing Benefit, it is likely that recipients will receive a claim form from the authority - the same is likely to apply to recipients of Income Support. The Department of Social Security should contact them advising them of their right to CCB.

In cases where both partners of a couple are liable for the personal community charge, they will each have separate accounts, separate charge notices and, if applicable, separate CCB credits. However, one partner must claim on behalf of both. If someone is incapable of acting on his or her own behalf it will be in order for someone else to act on his/her behalf.

If the CCB applicant is already in receipt of Housing Benefit or Income Support, the local authority will simply credit their community charge accounts with a full 80% CCB - everyone has to actually pay 20% of the charge. In other cases local authorities will assess the applicants financial circumstances in much the same way as Housing Benefit is calculated. This means that anyone holding more than a given amount of capital - £8000 - will not be entitled to CCB.

In other cases the local authority will compare the persons needs or "applicable amount" with their weekly income. Where the income is equal to or less than the relevant applicable amount, the usual 80% credit will be made. If the income exceeds the applicable amount, the excess will be multiplied by a taper of around 15% and this will be deducted from the 80% CCB. The net result will be the amount of CCB credited to the claimants community charge account.

> *"None of us will escape paying some or all of the Poll Tax, one way or another."*

Where partners are concerned - and remember the CCB claim can only be made by one of them - their joint income will be assessed and then compared with the applicable amount for the couple. If they are entitled to CCB, the amount concerned will be divided between them and the relevant amounts credited to their separate community charge accounts. They will then, separately, be expected to pay the balance of the liabilities.

Charging authorities will be empowered to impose financial penalties on anyone who knowingly provides misleading information or who refuses to provide information when required to do so by the Community Charge Registration Officer. Magistrates Court Orders will be used to recover any outstanding community charge arrears. They will use such devices as attachment of earnings orders, deductions - at source - from social security benefits, distress, or bankruptcy proceedings. If wilful refusal to pay is suspected, and the remedy of distress does not produce sufficient funds to pay the debt, the person could be imprisoned.

One way or another, none of us will escape paying some or all of the Poll Tax.

Local Association News

Belfast

Sir Robin Kinahan, President of the Northern Ireland Association, recently opened the first office of the Belfast and District Branch of ASBAH. An event appropriate in the 21st year of the Branch's existence with a membership of over 600. Molly Stewart has taken up the two-day-a-week post of Administration Secretary in the new offices (Room 305, Bryson House, Bedford Street, Belfast BT2 7FE) and will be offering a co-ordinating service to members.

Back Row: Sir Robin Kinahan (President N.I. Association), Ann Gillilan (Chairman Belfast & District Branch), Jim Piggot, FRCS (President Belfast & District Branch). Members: David McAleese, Julie Carleton and Leonard Tarr.

Yorkshire

The Barnsley Association was recently presented with a cheque for £318 which was raised by the tenants and customers at the Cranberry Public House in Barnsley.

Severe Disablement Allowance:

How to claim.

By Linda Avery.

July 1989 marked the end of another school year and for thousands of young people it was also the end of their schooling altogether.

For those youngsters with disabilities it will also mean that they can now claim social security benefits in their own right and will therefore be entitled to benefits for which they have hitherto been too young to qualify. For severely disabled young people, the main benefit is Severe Disablement Allowance - SDA.

> ***"SDA holds several advantages for young people. Those aged under 20 do not have to be assesssed for their degree of disablement."***

This is a weekly cash benefit that is non means tested and non taxable and which is non contributory - so does not need a previous National Insurance Contribution record. SDA is worth £26.20 per week, plus £15.65 for an adult dependant, such as a husband or wife, or someone looking after the claimants child, plus £8.95 for each of the claimants children (This will be paid in addition to Child Benefit).

SDA is paid to people who have been incapable of work for which an employer would pay, for at least 28 weeks, and:

- who are under 20; or
- who have been assessed as at least 75% disabled; or
- who are receiving various 'passporting' benefits, including Mobility Allowance, or Attendance Allowance; or
- who are already receiving the old non-contributory Invalidity Pension on November 28th 1984.

SDA holds several advantages for young people. Those aged under 20 do not have to be assesssed for their degree of disablement, nor need they be receiving any of the passporting benefits - although it is true to say that most will be receiving Mobility and/or Attendance Allowance.

The claimant must show that s/he is "incapable of work by reason of some specific disease or bodily or mental disablement". Note, though, that the emphasis is always on the incapacity for work, not difficulties in obtaining work. So quoting such problems as high local unemployment, or that the kinds of jobs the claimant wants are not available locally, will not help his or her case. The incapacity must result directly from the claimant's illness or disabilities.

The rules state that the claimant must have been incapable of work for at least 196 days before receiving SDA. But this can include days which fall before the young persons 16th birthday, making it possible to put in a claim in advance so as to ensure that actual SDA payments can start as soon as the young person reaches his or her 16th birthday.

The claimant must normally be present in Britain to receive SDA and must have spent at least 168 days of the 196-day qualifying period here. However, this condition can be waived if the claimant is living abroad with a parent who is serving in the forces. Note, though, assuming the claimant is under the age of 20, he or she must, since birth, have lived in this country for at least 10 years.

Being in full-time education does not automatically exclude young people from SDA. A young person who is under 19 and either still at school or undergoing full time non-advanced education may still qualify. Everything depends on the type of education and the number of "tutor contact" hours which the course involves. "Tutor contact" means that lesson breaks such as lunch, coffee, tea, private study hours or free periods are not counted within the hourly calculations. So, if the number of tutor contact hours the young person receives per week is 21 or less, the type of education used will be ignored and the young person will qualify for SDA.

> ***"The emphasis is always on the incapacity for work, not difficulties in obtaining work. So quoting such problems as high local unemployment, or that the kinds of jobs the claimant wants are not available locally, will not help his or her case."***

If the number of tutor contact hours is 21 or more per week, the Department of Social Security will want to know whether they would be "suitable for persons of the same sex and who do not suffer from a physical or mental disability". Suppose then that a young person receives 24 hours of tuition per week, but 4 of those hours includes lessons in wheelchair use, those 4 hours would not count. In the same way, if the young person is in the same class as non-handicapped students, but, unlike the others, uses Braille texts or a signer, none of those hours would be included. Even if the teaching methods are exactly the same, if the disabled youngster needs tutor contact in certain subjects in order to keep up because of their disability, again, the extra hours do not count.

Claims for SDA should be submitted on Form N1 252 and accompanied by a doctors' statement explaining the incapacity for work.

Benefits on holiday;

how to maintain them.

For most of us, the idea of a holiday abroad is no longer a luxury but a way of life. For those living on state benefits however much will depend on their ability to have saved any money and whether or not leaving the country is likely to affect their continued entitlement to benefits.

Retirement and widows pensions can continue to be paid for as long as the person is away - indeed, if the recipient is likely to be away for more than three months, they should contact the local Department of Social Security office to make arrangements for the pension to be sent out to them. For almost all other benefits, however, there are time limits and various other restrictions to consider.

If you have been incapable of work for 6 months or more, short periods spent abroad should present no problem. But if the stay is likely to be extended the social security office will scrutinize your case very carefully. If the Secretary of State - in whose name decisions are taken - decides you should not receive benefit whilst you are away, there are no channels of appeal against that decision. However, if your GP or social worker can write a note explaining your need for a holiday, this can be passed to the social security office with a request for the decision to be reversed.

If you receive sickness, maternity, injury or invalidity benefit and you have been ill and incapable of work for 6 months, you will usually be able to continue to receive those benefits during any temporary absence from the UK, even if the absence is purely for holiday purposes. However, if your sickness or incapacity has been for less than 6 months, benefit will be stopped. There is an exception to this rule, in that, if you show you are going abroad temporarily for the particular purpose of being treated for an illness or disability which first arose whilst in the UK, benefit may continue to be paid. The key word here is "treated", so that mere convalescence would not count.

People who are receiving Mobility or Attendance Allowances can continue to receive them for the first 26 weeks spent abroad and, subject to the discretion of the Secretary of State, this may be extended if they are abroad to receive treatment.

If you have a "carer" who is receiving Invalid Care Allowance and s/he accompanies you or your trip, s/he will continue to be paid the allowance though it must be shown they are caring for you up to 35 hours per week and that you are still receiving Attendance Allowance. Carers who go abroad alone can continue to receive ICA for four weeks.

> ***"If you show you are going abroad temporarily for the particular purpose of being treated for an illness or disability which first arose whilst in the UK, benefit may continue to be paid."***

Income Support will continue to be paid for the first four weeks of any temporary absence abroad, provided the payee does not have to 'sign on' for work. Again, if the need to sign on has been waived due to sickness or disability, then the six months or less rules, noted above, apply.

Those receiving Severe Disablement Allowance will be subjected to the same rules. Also, remember that if you are still within the 28 week qualifying period for this allowance, any absence abroad for more than 28 weeks will means that you will have to start the qualifying period all over again on your return to the UK.

If you go abroad to an EEC country you can continue to be paid Statutory Sick Pay, subject to the usual conditions, but if you are outside the EEC at the start of your sickness this relieves your employer of any SSP responsibility - the same applies to Statutory Maternity Pay.

Child Benefit payments will continue for the first eight weeks of any temporary absence abroad, although it can be paid for a longer period if the child is away specifically for the purposes of medical treatment. If the child is attending school abroad then the benefit will be paid up to a maximum of three years.

Unemployed people are treated somewhat differently. Usually, people on unemployment benefit will not be able to continue receiving it whilst abroad since they are required to remain available for work. Similarly, holidays taken within the UK will be severely limited since the person must be able to return for an interview should a suitable job vacancy arise. You will be expected to provide an address and telephone number at which you can be contacted immediately.

However, if you have been receiving unemployment benefit for at least four weeks and then go abroad in search of work, you may still be entitled to the benefit up to a maximum of three months.

The Department of Social Security issues various leaflets relating to benefits and holidays abroad. Contact your local social security office for details, or write to:

DoSS Overseas Branch,
Newcastle Upon Tyne.
NE98 1YX.

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With Frizzell's travel insurance.

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The main benefits of the scheme are that:

- A very wide range of cover is provided both in respect of all members of the party, as well as the car if appropriate.
- The insurers are aware of the special needs of people with spina bifida and/or hydrocephalus and have agreed that parents or guardians can make the decision to return if a medical emergency arises and no appropriate services are available locally. (Central ASBAH can recommend medical experts in many countries.)
- An English speaking emergency service is available to provide assistance in the event of an emergency of any description.
- It provides families with complete "peace of mind" concerning insurance cover which is not always so when arranging a package holiday, or making individual arrangements.

The package is provides insurance for a two week holiday in France for two adults and two children which would cost just £62.50 and there are no special exclusions relating to spina bifida and hydrocepahlus.

If it should be necessary to return home for medical attention, members may want the whole family to return at the same time; this also is catered for in the package.

Frizzell Carefree Travel Insurance is very simple to arrange, by completing the straight forward application form enclosed and returning it to Frizzells with your remittance or Access/Visa Number. If you need urgent cover, telephone Alan Gamblin or Janet Read on 0202 292333.

As you can see any worries you may have over holiday insurance, and the difficulties that obtaining it may entail have been thought of, and overcome by Frizzells.

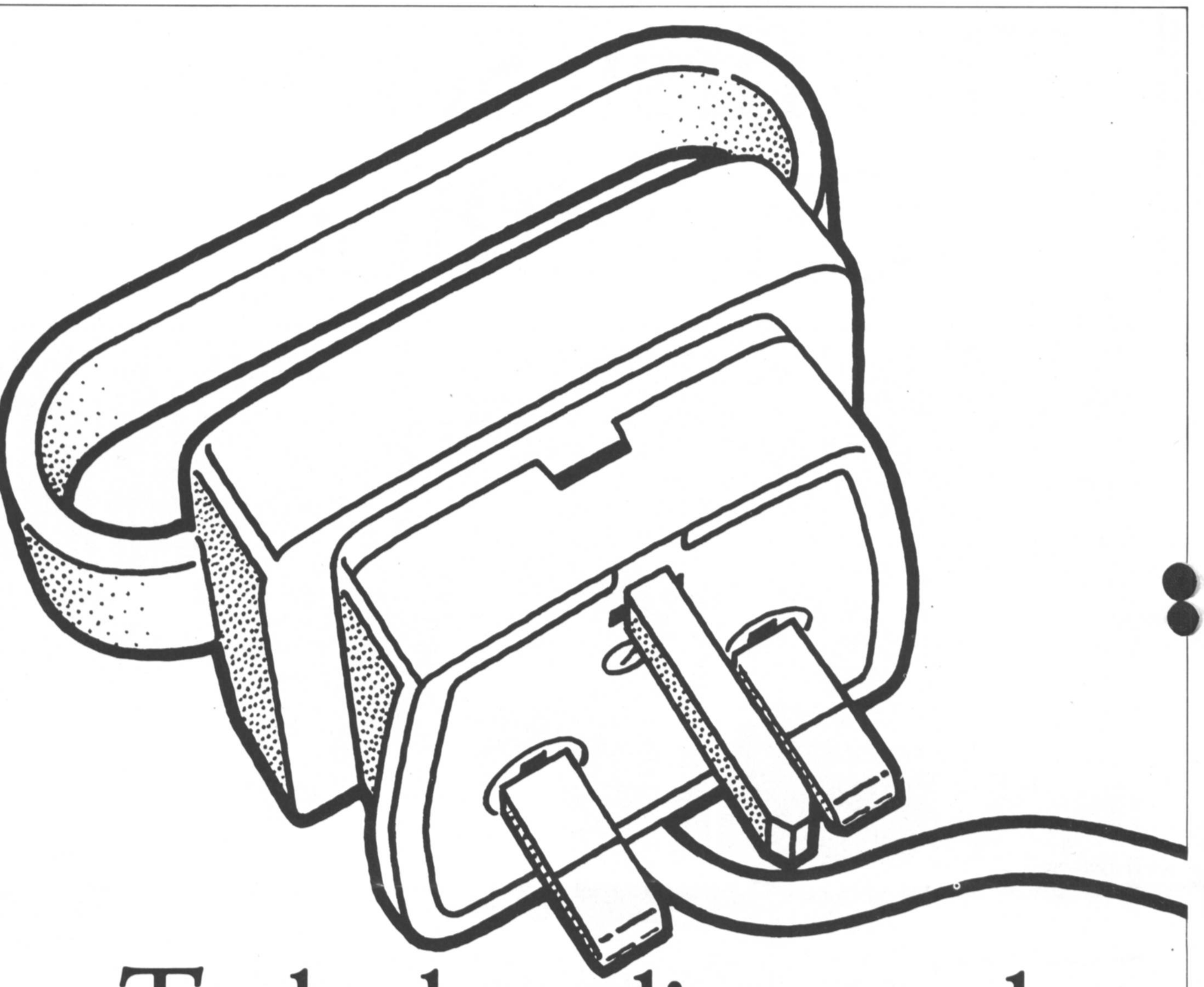
The first Schools' Chatathon.

17 YEAR old Amanda Ellerbeck was chosen by a panel of three distinguished judges - TV presenter Gyles Brandreth, author Roald Dahl and Charles Kennedy MP - to win the first Schools Chatathon. Over 20 schools from as far as Derby and Livepool encouraged pupils between 15 and 18 years of age to enter the competition to find the "Junior Conversationalist of the Year".

The two-day event was sponsored by St Nicholas Montessori and televised on John Craven's Newsround. Contestants had to speak for eight hours and topics were diverse. Ranging from "eating out" and "the environment" to "parents" and "heart-throbs" and ended on "the power of the media".

Amanda, who attends Leweston School in Sherbourne, Dorset is studying for "A" Levels at present. She had originally entered the competition in order to raise funds for ASBAH and support a friend at school and was quite unprepared to win. Points were awarded on fluency, humour, clarity, vocabulary, courtesy and, most important, the ability to listen.

Amanda Ellerbeck, being presented with the winner's plaque (top) and (bellow) talking away to her win in the final with Kelvin Hall.



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Rates: £3 for 30 words max; £4.25 for 30-45 words; £5.50 for 45-60 words.
Cheque or postal order payable to 'ASBAH'

Adverts for the next LINK (September/October) should be in by 25th August. Send to: The Editor, LINK, ASBAH, 22 Upper Woburn Place, London WC1.

HOLIDAY ACCOMMODATION

BORTH, Nr Aberystwyth. 6-berth de luxe holiday home. Licensed site. Suitable for wheelchair users who live independently. Details: Mrs J. Carter,
1, Meadow Road, Craven Arms, Shropshire.

ISLE OF WIGHT. Very well equipped chalet with easy wheelchair access at **Brambles Chine, Freshwater.** Sleeps 6. Indoor heated pool, club, shop. Details: Ring or write: Mrs S. Gully, Old Princelett, Apse Heath Sandown, Isle of Wight. Tel: 0983 863354.

SELSEY, Sussex. Six berth purpose built fully equipped mobile home. Ramp access. Site near sea. Pool, club, etc. Details: Mrs C. Bugden, 27 The Grove, Sholing, Southampton SO2 9LT. Tel: 0703 444921.

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NIPPI 49cc. Low mileage. Daughter has progressed to car. Including chair bracket. Ideal first vehicle. £1,000. Less than half new price. Telephone 0527 73221.

CONTRIBUTIONS and articles for Link are always welcomed. If you have a topic you wish to air, or you have photographs of interesting events, why not write to:-
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Link Magazine,
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22, UPPER WOBURN PLACE,
LONDON WC1H 0EP
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