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KING EDWARD'S HOSPITAL FUND FOR LONDON

King's Fund Centre

COPING WITH PHYSICAL HANDICAP IN THE COMMUNITY - CONTACTS & INFORMATION

Report of two study days held at the King's Fund Centre on 21 February and 19 April 1979

King's Fund Centre
126 Albert Street
London NW1 7NF

August 1979

INTRODUCTION

It was a privilege to be invited to write the introduction to this report of the two study days which were organised by Diana Irish in February and April. I attended both days and had been glad of the opportunity to listen to the very varied and interesting papers.

However, I felt that writing this introduction was not going to be a very easy task; each of the two days was completely different and it would be difficult to draw them together into a whole single minded introduction. After some reflection I came to the conclusion that the differences between the two days seemed to unintentionally symbolise the enormous gaps that still exist between disabled consumers of the health and social services and the variety of professionals who work within the services. An introduction would need to recognize those gaps and could only be a broad open-ended comment on the two days.

The first day brought out the vulnerability of disabled people. They have a vital need for sincere and understanding communication with professionals and the public if they are going to be social survivors in a world which puts increasing emphasis on physical and intellectual efficiency. The speakers described some imaginative ways in which disabled people are communicating with the public and professionals, and discussed the role of consumer pressure groups and voluntary organisations and community health councils.

The speakers on the second day brought out the concern that enlightened professionals feel for their clients and looked at some specific ways of improving contacts.

All the speakers made it quite clear that the maze of systems, which have evolved over the last few years with the aim of helping disabled people, often result in just confusing them and some people <u>still</u> slip through the net and receive no help at all.

There has to be improved methods of communication between disabled people and professionals and public. One way of achieving this is for pressure to be exerted on service planners by individual disabled people and voluntary organisations and community health councils. The pressure must, however be carefully planned, well-informed and preferably supported by professionals who are already in close contact with clients.

On both days the delegates were divided into four groups and each group was asked to comment on a different extract from my book 'Holes in the Welfare Net'. The extracts described specific problems of disabled individuals: the reactions of the delegates were a mixture of disbelief, sympathy for the individuals, shock, remarks that 'these cases were not typical' and ideas to prevent such things occurring in their own areas.

When I had been writing 'Holes in the Welfare Net', which is based on informal discussions with disabled people and their families, my reactions had been similar because the sort of things that happen to some disabled people are certainly amazing and shameful. So shameful, indeed, that none of us really wants to believe their stories and we tend to take refuge in the comforting idea that such 'cases' are not typical.

Unfortunately, there are too many 'untypical cases' in existence. A few get into the books and papers of researchers, a few are reported in the daily press or on television or radio, but hundreds of others exist in a sort of limbo - unheard of, lonely, and missing the help that they should be receiving. For this reason articulate disabled people have a role to play in speaking up and telling professionals about their own needs and the needs of those who are less articulate; and professionals have a role to play in being politically active.

Being 'political' can mean anything from a few honest words at staff meetings to using local and national media for publicizing injustices and the poor management of services. Being 'political' may mean making oneself unpopular with colleagues and seniors and putting one's career at risk. Being 'political' will ultimately result in getting better services for disabled people and will have the long term effect of creating better services for a future generation of professionals to work with; it can be a means of breaking the chain of inherited bad services which cause so much despondency amongst committed professionals and so much loneliness and suffering amongst disabled people and their families.

The ability to communicate - to describe needs and share ideas and give information - is one of the strongest weapons in the battle to improve present services and influence future services. For this reason I applaud the two study days for they not only illustrated the many gaps which still exist between disabled people and professionals but also drew attention to the courageous and imaginative efforts being made by some people to draw together the two groups through the means of better communication.

Maureen Oswin
August 1979

King Edward's Hospital Fund for London

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Report of a study day held on the 21 February, 1979

Chairman - Malcolm Johnson, Secretary for Policy and Research, Personal
Social Services Council

Welcoming the participants to the Centre, the Chairman said that the purpose of the day was a sharing exercise - the sharing of common knowledge and experience. In addition to the speakers the Chairman knew that many of the participants in the audience had examples of good practice in the dissemination of information to disabled people and he hoped they would share these during the discussion sessions.

THE ROLE OF THE PROVINCIAL NEWSPAPER

When Pat Saunders, disabled in middle age, had decided there should be a regular newspaper column for disabled people, by a disabled person, he had never written a line for publication in his life. The first thing to do was to build a resource bank, cross-referenced he said. And as editors were extremely hard men to convince, it was necessary to have a power group to take up cudgels on your behalf.

Pat Saunders now had a weekly page, with his own logo, in the Portsmouth Evening News. It not only informs the disabled, it also teaches the able bodied, and it influences the decision makers. You must write for the maximum audience Pat advised. This meant a chatty style and some sacrifice of completeness for readability. Making it lively also involved the presentation of information through personalities - thus he had interviewed the director of social services. The editor also required reliability of copy flow, so Pat worked six weeks ahead.

You cannot write a weekly column without becoming a social service warned Pat, he receives up to six letters a day and about the same number of telephone enquiries. You find also that the articles become an exchange point, for equipment, such as wheelchairs, and for ideas.

A weekly popular newspaper column filled a gap in the media. It did not overlap the national magazines of organisations for the disabled, for most of these were not read by nine out of ten disabled people. A newspaper was read by everybody.

DIAL - DISABLEMENT INFORMATION AND ADVICE LINE

Describing how the phone in service, DIAL (Disablement Information and Advice Line) was born, Ken Davies said in Derbyshire we knew there was a local need for information. DHSS leaflets often required interpretation and often you needed interpretation of the interpretations. It was a very confused field and people generally looked for advice.

Six months were spent in the planning stage to determine what sort of service was really required. Was it just information, or information and advice, or information, advice and physical help? Should the service act as a pressure group? Should it be based in the high street, not associated with the disabled as such, or should it be linked with the social services department? The one thing we found was that people were very put off by bureaucracy reported Ken.

We were aware we might create dependency simply by creating a service. We thought one of the basic principles was to give information to help people to help themselves said Ken. To inspire confidence, callers were rung back, if the information could not be given immediately. This was done even if the details could not be obtained. It was also decided to keep conversations short. Ken was not sure now that it was necessarily a bad thing to allow people to run on, one may often find that the first thing a person asked was not what they needed to know at all.

In training people to run the service it was important, as well as becoming familiar with the literature, to make contact with local bodies - the Citizens Advice Bureau, the Disablement Resettlement Officer, Samaritans, people in the DHSS, the library service and so on. Posters and literature were sent to day centres, hospitals, health centres and libraries. The local press and radio were used for initial publicity.

Most, but not all, the volunteers who came in one day a week each to run the service were disabled. We have a lot of requests for information, but far more want advice or interpretation reported Ken. Many people asked for practical help. Enquiries were at the rate of five or six a day. Some callers simply wanted to talk, and volunteers often find themselves in the role of the 'good listener'.

There were now twenty four similar local groups, not all calling themselves DIAL. A steering committee was piloting the formation of a national body (1) and attention was being given to providing a co-ordinated source of common information.

THE BENEFITS SYSTEM - THE ASSUMPTION OF CHALLENGE

A game of snakes and ladders for real was how Irene Loach of Disability Alliance (2) described the benefits system. She discussed why it was confused and why advice was needed at national and local level. People simply do not know what exists, and when they find out, they do not necessarily know how to claim, or if they want to appeal, how to do so said Irene.

There were contribution related benefits, non-contributory benefits extent of disability benefits and means tested benefits. The first were derived through contribution records. An example of the second was the invalid care allowance. The attendance allowance and war and industrial injury payments were examples of the third. All had different methods of assessment. Means tested benefits such as supplementary benefits, rate rebates and family income supplement, all had slightly different requirements too.

The Disability Alliance had shown to the DHSS that the marital status provisions were extremely discriminatory against women. Other benefits were limited by age. Success in areas of discretion depended on presenting a case well to a tribunal. There was the passport system whereby one benefit entitled to others - to free prescriptions, for instance, or free dental care. There were variable social service provisions, like the concessionary fares for which each local authority had a different scheme.

There was the question of overlap. Was a person better off with a rent and rates rebate or supplementary benefit? At the moment we would say you were better off claiming supplementary benefit, as a result of water and sewage rates going up so much explained Irene, these were not included in rate rebates.

A disabled person was transferred from invalidity pension to unemployment benefit. Because he could not get a job, his income was reduced for years to come. The time of claiming could be critical, where the amount was set for a year ahead, irrespective of changing circumstances, ie the birth of a child.

The assumption behind the benefits system is that clients will challenge decisions said Irene. In fact clients often did not. This was especially so with disabled people, many of whom did not want to be blackmarked as 'trouble-makers'. Also it was hard to get hold of information on which to challenge. The 'A' code, for example, on which discretionary decisions was made, was not available to clients. It was very difficult to challenge a doctor's report.

Local advice groups could not only provide facts and advice, but also the key that was needed. They took the fear out of claiming.

The confidence to claim was the great thing said Irene. Advice groups provided a client-orientated service, whereas the DHSS was a benefits-orientated service. The problem was for local groups to keep up to date. To do this they needed to keep in touch with other organisations, locally and nationally. The Disability Alliance wanted a system of benefits based on severity of disability.

COMMUNITY HEALTH COUNCIL EXPERIENCE

The North Surrey Community Health Council operated from a shop front premises. About six people each week wanted to know how to get aids, social services, wheelchairs or benefits said Joan McGlennon, secretary to the Council.

So the CHC had organised an Aids to Independence exhibition. (3) It had attracted some eight to nine hundred people over two days. Although it was disappointing that very few professionals from hospitals or social services had attended admitted Joan.

As an example of the ignorance of what was available, she cited the possibility of getting dental treatment through the community dental service, if it could not be obtained through the ordinary NHS dental service. This was not mentioned in the NHS pamphlet NHS 4 on dentistry.(4) Even community nurses were often unaware of whom to approach for aids which broughtindependence. There should be a national centre to evaluate such equipment. Lack of knowledge about adaptations to homes could lead to disabled people seeking residential care said Joan.

A young person whose problem was mainly physical remained in the geriatric ward of a mental hospital because the staff had not realised there was no central admissions policy for Cheshire Homes. There was a tendency to give up too easily, to accept that if one establishment said 'no', the others will as well added Joan.

There was also the hospital where people being prepared to go into the community by living in a flat could not learn how to feed themselves, because if they had cooked their own meals it would have upset the catering department's accounts.

DISCUSSION GROUPS

Maureen Oswin's Book Holes in the Welfare Net (5) was used to provide the four discussion groups with practical problems to discuss. (see Appendix)

1 The vulnerability of the newly disabled person led to a discussion of counselling. The group felt this could not be left to a professional to do casually. On information dissemination, the group heard about the Wessex Medical Library Project. One problem was that many disabled people were not known to social service departments. The group discussed the idea of a 'named person' and the squabbles between organisations.

2 This group did not see access as the major problem for disabled people, and in any case the issue was complex. It was not just a question of physical facilities, but of educating employers and others. Siting was important, a building was not accessible if the car park was half a mile away. The group felt that everyone should have access to decision making and reports which affected them, not just disabled people.

3 Home care should be primarily financed by health authorities and social service departments, but joint funding meant that in five years one or other had to pick up responsibility. The group wondered whether voluntary bodies might not better take over. A 'fixer' who could operate across the board was suggested and local pressure groups had a part to play. However even good information schemes had limitations, for instance, Camden's booklets only went to registered disabled people. The group also discussed the difficulties for parents with handicapped children and agreed that parents were extremely protective.

4 Housing was perhaps the most basic problem of all, and there was a lack of coordination of services in the community. The group considered whether it should be a question of going from the grossest imperfection only to the greatest perfection. Was enough attention given to halfway housing, many disabled people would be happy in such adapted housing. This group also agreed that there should be an 'advocate' for the disabled person. The suggestion was made that the district community physician might be a leader.

PROJECTS AND CONTACTS

Throughout the day several interesting projects were mentioned, and some of these have been listed below, together with other organisations that were mentioned as providing information and help to disabled people.

The Wessex Regional Medical Library Project

Mr R B Tabor explained the pioneering work now being done by the medical library at Southampton. This consisted of the establishment of a patient information service and a research project on the provision of information about statutory and voluntary bodies related to illness. The research project was being funded by the British Library.

Citizens Advice Bureaux

Jeremy Leighton said that the CABs could provide information for disabled people. He stressed that although an agency like CAB was a national network, it was not something provided from outside, each bureau was a local group.

Radio London's Confidential Phone In

Miss K A Davies broadcasts information to disabled people on BBC Radio London's Link Line. After such broadcasts she deals with many hundreds of enquiries through a confidential telephone service.

Brent Association for the Disabled

Nancy Robertson reported that the Brent Association for the Disabled worked across the range of disabilities. They had found housing associations useful in providing accommodation for disabled people.

Directory for the Disabled

Ann Darnbrough noted that the Directory for the Disabled was being updated and should be available in November 1979.

So You're Paralysed

Baroness Masham commended the Spinal Injuries Association book So You're Paralysed, which was a useful guide to those with spinal injury, available from the association at 126 Albert Street, London NW1.

Royal Association for Disability and Rehabilitation

Mr Bert Massey reminded participants that RADAR was very involved with all aspects of life for disabled people. Details of their publications were available from RADAR. 45 Mortimer Street, London WC1.

CONCLUSION

The Chairman regretted that there had not been much time for free discussion, but he hoped that delegates would be taking away some ideas.

A second study day was to be held on the 19 April for those applicants who could not participate on this occasion, and he hoped that some of the themes that had emerged during the day would be pursued on the second day.

Malcolm Johnson concluded with this aphorism - professional archipelagos create disabled islands.

Laurence Dopson
February 1979

King Edward's Hospital Fund for London

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Report of a study day held on the 19 April, 1979

Chairman - Malcolm Johnson, Secretary for Policy and Research, Personal Social Services Council

Having welcomed participants to this second study day, the Chairman explained that it was not intended to present a replica of the first study day. The programme had been planned around some of the themes that had emerged during the first day. Once again he hoped that participants would share their knowledge and experience, as they had done on the first occasion.

CONTACTS WITHIN A HOSPITAL

Gill Corney, a schoolteacher turned social worker, and now Counsellor with the Cheshire Foundation, stressed the importance of contacts being made within hospital when a person first becomes disabled, a time when the disabled person and their family were at their most vulnerable. Mrs Corney had worked in a teaching hospital offering a regional service with patients coming from a wide area.

For the patient in a sudden emergency, such as the victim of a road accident, the family very often were faced with immediate problems, ie money, or the need for temporary care of the children. It was important for the social worker and her movements to be known to the ward staff so that they could say 'the social worker will be in first thing tomorrow to help you.'

After the crisis came the plateau period, when the multi-disciplinary team brought their skills to help with the problems. Relatives had got over the initial shock and settled down to a pattern. There was always a false sense of security at this stage explained Mrs Corney with the social worker taking the lesser role, nevertheless she had to keep in touch with patients and relatives in a variety of ways, particularly by being available if they had a problem. Weekly meetings of members of the team and the maintenance of a Cardex record demanded a lot of commitment but were vital. So many people were helping that good consultation was essential.

Then came the second crisis period for the patient and his family, when it became clear that the patient was going to be left with a considerable degree of disability. The social worker, having already learned from the family what the problems would be, now had to help them to cope. It was at this time that the social worker took the major role. The patient had come to realise the damage done to him and it was often not necessary to spell it out. But so far as the family was concerned, there was a sort of panic. There is nothing more we can usefully do the doctor had told them, so the time had come to consider discharge. This may terrify the patient and his family and an enormous amount of emotional adjustment may be necessary by all of them. The social worker will explain and arrange community services and help with staggered discharges, whilst the ward sister will arrange for the domiciliary nursing services to be available.

In all this the social worker required to have a good relationship with the other members of the team, but particularly with the consultant stressed Mrs Corney. How did the social worker get access to the consultant?

It was not difficult if you made arrangements to see him at the end of clinical sessions or at joint interviews.

In the case of patients admitted for diagnosis of multiple sclerosis it had not been the practice at her hospital to tell the patient after the first attack, because the diagnosis could not be confirmed at that stage. Mrs Corney had tried however to have a word with any such patient admitted to the hospital. Most people in the strange surroundings of a hospital were happy to talk to a social worker, who could thus get a fairly clear picture of the patient's background. The patient was given the social worker's telephone number and encouraged to contact her if there were any difficulties.

If you sold yourself well enough on the initial contact people would remember said Mrs Corney, and it was reassuring for the patient who had to be readmitted to hospital to know there was someone available whom they already knew.

Contact was maintained in the outpatient department when the social worker was a member of the team. Sometimes people discussed their problems at length, but the social worker never sought to impose assistance on them before they were ready for it. In the Outpatient Department you could keep an eye on people who might not know what illness they had, and who had problems they refused to recognise. If you were there, people would talk to you, and so often patients felt themselves part of a large bureaucratic machine, being seen by a different doctor each time. If there was just one person they recognised such as the social worker, this was a great help.

The social worker could often sort out troublesome problems over appointments, such as ensuring that all necessary clinic appointments, eg neurology and ophthalmology were arranged on the same day rather than involving patients in arduous double journeys.

Ideally the community social worker should carry on where the hospital social worker stopped, but Mrs Corney considered the community social worker poorly trained to deal with disabled people. Much of the emphasis in the community social worker's training had been on the generic, and the bulk of concern in social service departments was on child care, so the handicapped and the elderly were lumped together and dealt with in the main by untrained workers.

There were some disinterested GPs who did not support patients with long term illness. It was too common an experience that once a GP had labelled someone as disabled, that GP no longer took an interest, and every problem was put down to 'your multiple sclerosis'. An additional difficulty was that neurology clinics became overloaded, and the patient eventually felt that no one cared, and often in desperation such a patient would ring the hospital social worker.

The hospital social worker was a pivot for many of the services for such patients both in and out of hospital, for instance the hospital social worker could also help where the community social worker felt the patient needed extra help such as holiday admission. While in theory there were many people and services available to help handicapped people, many patients end up with no help at all concluded Mrs Corney. In many instances the hospital social worker could well be the most appropriate person to act as a coordinator.

Discussion

In answer to Miss Duckham, of the Consumers Association, Mrs Corney said she thought social work as a profession should provide better knowledge of physical disabilities during training. Too often social service departments saw help only in terms of providing practical services, however disabled people also need help with emotional problems. Another participant said that in child care and care of the mentally handicapped, certain duties were statutory but there were no statutory duties in work with disabled people. This same participant said that when she had been a member of an area social work team, she had been annoyed at the referrals made by medical social workers; and had felt that there should be more emphasis on follow up work by the hospital social workers themselves. Mrs Corney agreed and said that she had followed up people within a reasonable distance. However she too had been horrified by some practices. Meals-on-wheels for instance should be arranged before discharge and not left to the community social worker to arrange once discharge had taken place.

Linda Tuckey, social worker and researcher, wanted more liaison between social worker trainees and medical students, student nurses, student occupational therapists and physiotherapists.

A participant referred to resistance not only from nurses but from other tutors to efforts to deal with the sexual problems of the disabled.

A Yorkshire participant complained that local authorities refused to implement sections of the Chronically Sick and Disabled Persons Act. (6) Another contributor said that the group who were physically and mentally handicapped often missed out. Mrs Corney agreed with this and said that in the village where she lived they had started a Gateway Group based on the health centre with the aid of the WRVS. Another participant commended to health visitors and social workers local Mencap societies.

PUTTING PEOPLE BACK INTO THE COMMUNITY

Barbara Hoole, an occupational therapist working as a social worker in the north west regional spinal unit at the Promenade Hospital, Southport described planning for discharge from the unit, which had a large catchment area. This was a forty bedded unit and the average length of stay was five to seven months, so there was a long period in which to plan discharge.

During the first few weeks after admission the hospital social worker wrote to the appropriate social service department. A joint visit to the home to which discharge was to take place was made within the first couple of months, in order to initiate plans for weekend visits home which take place regularly as soon as the patient is well enough and his condition in a wheelchair became stable. The first visit home provided much background information for the rehabilitation staff, and is the first step in the patient's return to the community. It also gives the relatives and patient opportunities to work out solutions to the practical problems they will face.

The nursing staff look after community nursing liaison. District nursing sisters were invited to come to the unit and see how the nursing staff coped with the patient. At the same time the relatives were gradually brought into the care of the patients. For instance before a tetraplegic went home, the relatives usually looked after the patient for a couple of days on the ward under the supervision of the nursing sister.

From the initial visit the Unit tried to build up a good liaison with the local authority services. Some authorities had already experienced work with spinal injury patients but others had little experience and would use the expertise of the Centre to a greater degree.

On long term follow up Mrs Hoole admitted that they had underestimated the volume of work and the employing authority's financial resources and so had not been able to realise the initial idea of follow up visits. However, the patients came back for check-ups and were seen then. She agreed that after discharge the first few weeks were vital for social work support, it was then that patients were so vulnerable.

Discussion

In answer to Joan McGlennon, Secretary North Surrey CHC, Mrs Hoole said that they had found that many voluntary homes in the north were not able to cope with high spinal injury cases. An Occupational Therapist participant said that she liked to know of spinal injury people in her area within forty eight hours of injury occurring so that she could visit. She also wished hospitals would arrange for mid-week 'weekend' discharges.

With regard to sport , Mrs Hoole said that a small paraplegic sports club was attached to the unit and certainly sport should form a vitally important part of a rehabilitation service, however it must be remembered that not all spinal injury patients would automatically be interested in sport, just as many able bodied people were not interested in it.

Mrs Hoole agreed with a participant on the importance of sexual counselling. The Chairman commended the work of SPOD, Sexual and Personal Relationships of the Disabled. (7)

CHOICE MEANS HAVING INFORMATION

Ann Darnbrough a CHC secretary and author of the Directory for the Disabled, looked at vicious circle breakers. Choice was not possible unless the basic issues were sorted out, once the basic essentials were got over it was however as important to have the frills. To make choice, the disabled person needed as much information as possible on as wide a range of subjects as possible. CHCs had a role to play in providing information in an appropriate form, and a great deal of information was available in regard to holidays, access to theatres, restaurants, leisure activities, travel etc. Why did disabled people seem to have so little choice in the way their lives were run? Why were they so often relegated to second class citizenship?

First there was the theory of low expectations - if expectations were low, results were low. Low expectations among disabled people themselves, among caring agents and among the general public led to the depressed lives that some disabled people lived. Acceptance of the tradition of gratitude led to a poor self-assessment, because one did not ask for things that would enrich life. Life was not very much fun unless some risk was involved. Very often disabled people became very shy said Ann Darnbrough, they were used to people talking over them. As a result the caring agencies - voluntary and statutory - did not realise the degree of interests that a particular disabled person had, so caring agents went back to the Victorian attitude of providing and being patronising.

Disabled people did not necessarily enjoy going on holidays in groups, and if someone did not feel they wanted to share, why should they? Did one always have to go to a holiday camp if one was disabled?

There were officers of branches of societies for the disabled who were not prepared to see that their members were sexual beings. There was a lack of understanding because the needs were not brought to the notice of the general public. There was over protection. Ann defended the organisation, Sexual and Personal Relationships of the Disabled against criticism made during the morning session. It was a tiny organisation but she knew many members who had an understanding in a difficult task. She recommended that participants read Dr Wendy Greengross's book Entitled to Love(8) which looked at the difficulties for disabled people as well as discussing the attitudes of staff caring for disabled people.

On a more optimistic front there were a number of vicious circle breakers, such as British Rail travel for disabled people, air travel facilities, Open University courses, etc. In the USA, Greyhound coaches, the San Francisco Underground and the Los Angeles buses all catered for disabled people. In Britain there were the recent Jay Committee (9) recommendations and those of the Silver Jubilee Access Committee report. (10)

The Directory for the Disabled(11) had first appeared in 1977 and a further edition was due this year with a new chapter on education and other chapters covering every aspect of a person's life. Hopefully the price would be low enough to bring it within the pockets of many more disabled people, and Ann hoped that those present would endeavour to see that it was available within their own local libraries.

Discussion

A participant commented that lack of understanding was not only on the part of the general public. He complained that there were few facilities where a young person suffering from multiple sclerosis could holiday with his family for instance.

Another participant pointed out that under Section 15 of the Chronically Sick and Disabled Persons Act, disabled people could be co-opted to local authority committees. Mrs Corney said she encouraged disabled people to be on the management committees of residential homes, as she did not think that people who had no knowledge of disability could ever hope to make the right kind of decisions without some informed help. However a further contributor to the discussion denounced the Act as 'a lot of kidology'. The Derbyshire Disabled Association had written to every local authority about this matter, one had replied saying it would consider co-option, the rest had refused.

DISCUSSION GROUPS

The discussion groups were to consider the same examples taken from Maureen Oswin's book Holes in the Welfare Net as the groups at the first study day. Malcolm Johnson invited Maureen Oswin to comment on the examples the groups would be considering.

Miss Oswin said that surprise had been expressed at the first study day concerning the examples and that they could not actually happen. However they were factual examples of the difficulties facing disabled people in the community and when she had done the research for the book she had been shattered by the loneliness and depression of some of the people she had met. There had been the need for ordinary human kindness but also she had wondered where professional responsibility lay. Good professional people moved out of the areas where services were poor, so that those services became even worse. Miss Oswin felt that the professionals gave up too easily, saying they could do nothing. She challenged them to campaign for better services using local groups such as community health councils.

1 Physical access was not necessarily the biggest barrier, thought this group, who felt the example of the wheelchair person denied access to a post office was not typical. Handicapped people tended not always to look for alternatives. The biggest barriers were the psychological ones. How could the media help? The group felt that community health councils, regional and area health authorities provided a spring board. On the 'right to know' the group was concerned that a professional tended to make decisions for disabled people. Disabled people should be given more information to enable them to make decisions as individuals.

2 Another group stressed that everything depended on people meeting people on the basis of equality and suggested that jealousy accounted for a lot of failure to communicate. In hospitals it was the duty of staff on wards to supply as much information as possible. CHCs should produce 'easily disseminated' information.
How far did personalities affect communication? This question had produced a stunned silence in the group. If clash of personalities interfered the patient would certainly suffer. When doctors felt threatened and social workers insecure in their status, there was a general failure to accept comment and to regard it as criticism to be resented.

3 On the role of care assistants, a group heard about two local authorities with pilot schemes on the Crossroads model. There were difficulties of definition. The group accepted the education aspects of short term care. On the basic problem of lack of information the group felt it was important to build up local knowledge. This group also posed a number of questions, such as how to get local areas to respond to local needs, and would having disabled people on committees help?

4 This group was horrified at the housing case presented in Maureen Oswin's book. They did not think it could possibly happen in their areas, but one or two members did highlight the question of disabled children being taken into residential care. Compassion must have been lacking for Jean, the disabled girl, who was left in hospital.
The group heard about one borough that had appointed three paediatric occupational therapists who were undertaking a survey. Concern was expressed about teenagers who fell between two stools when they reached the age of 16. In the event of serious failures, and providing the family agreed, the group felt the local press should be involved.

Discussion

Maureen Oswin remarked that although the group was surprised by the case of Jean, the fact was that there were children living in hospital for all sorts of reasons, and very often not for medical reasons. Jean was only one of many.
One participant wanted research into the reasons why people went into long stay care, and another said money had to be provided for long stay care to be developed in small units.

Joan McGlennon of North Surrey CHC said that separate clubs or integrated facilities were slightly unnatural, however in her area if she wanted to go along to an ordinary group to pursue a hobby there was only one which she could attend, because of the difficulty of access.

CONCLUSION

Malcolm Johnson said that the key words he had picked up during the day were not the same as those on the first day.

<u>Communication</u> - with this was involved information

<u>Sensitivity</u> - an important concept

<u>Professional shortcomings</u> - the danger of becoming islands

<u>Process</u> - disability was something which changed over time and with it needs changed as well.

<u>Politics</u> - needed to achieve services

These two days had covered a lot of ground and yet there was still much to be explored in this field, he hoped that the King's Fund could continue the dialogue. Finally he commended the book Passage Through Crisis - Polio Victims and Their Families by Fred Davies. (12)

Laurence Dobson
June 1979

REFERENCES

1 DIAL groups, further information on developing a group can be obtained from Ken Davis, DIAL, Cressyfields, Alfreton, Derby.

2 Disability Alliance, 5 Netherhall Gardens, London NW3 5RN publish the Disability Rights Handbook

3 Pamphlet - Organise an Exhibition and Stay Sane, available from Secretary, North Surrey Community Health Council, 55 Church Road, Ashford, Middx.

4 Your Teeth and The NHS: pamphlet NHS4, November 1978; DHSS

5 Holes in the Welfare Net, Maureen Oswin, published by Bedford Square Press, at £2.95

6 Chronically Sick and Disabled Persons Act 1970 available from HMSO

7 Sexual and Personal Relationships of the Disabled, Brook House, 2-16 Torrington Place, WC1E 7HN

8 Entitled to Love, Wendy Greengross, pub. National Marriage Guidance Council in association with National Fund for Research into Crippling Diseases, Vincent House, 1 Springfield Road, Horsham, Sussex RH12 2PN

9 Report of the Committee of Enquiry into Mental Handicap, Nursing and Care: (Chairman Peggy Jay) London HMSO 1979

10 "Can Disabled People Go Where You Go?" Report by the Silver Jubilee Committee on Improving Access for Disabled People: (Chairman Mr Peter Large MBE) DHSS 1979

11 Directory for the Disabled; Ann Darnbrough and Derek Kinrade; pub.Woodhead Faulkner. Available November 1979, paperback version £3.60

12 Passage Through Crisis - Polio Victims and Their Families, Fred Davies;pub. Bobbs Merrill, Indianappolis, 1963

APPENDIX

The following topics were given to each discussion group.

extract from Holes in the Welfare Net

Disabled adults often find that their attempts to be independent are frustrated by people who are not prepared to be inconvenienced, and by local authorities who do not make provision for disabled people. A middle-aged woman who was disabled by multiple sclerosis, but able to propel herself into shops in her battery-operated wheel-chair, found it impossible to get into the post office because it had three large steps. This meant that a neighbour always had to fetch her social security payments for her. Not wishing to impose too much on the neighbour, the disabled woman phoned the post office to ask whether it might be possible for her to call herself at the office on an afternoon in mid-week when it was quiet, so that one of the assistants could come to the door to attend to her because she could not get her wheel-chair inside. Her request was refused.

Discuss whether access is the biggest barrier to coping in the community

How can the media help to prevent previous building and planning mistakes being repeated?

Discuss the right of the disabled individual to have access to information that will enable him to make his own decisions.

In developing computer information resources, what provision should be made to meet the needs of the disabled in the population?

extract from Holes in the Welfare Net

'What will happen when we die?'
In the sadness of missing her son, Mrs Woods was still comforted by knowing that Dick had 'gone first'. All parents fear the future for their handicapped sons and daughters. The dread of their son or daughter having to go into a large institution motivates elderly women to struggle on alone, long after being widowed. They lift, dress, wash and feed their middle-aged disabled children, and push heavy wheel-chairs to the shops, ignoring their own increasing infirmities. If the disabled person becomes aware that the mother's efforts to keep him at home are becoming too much for her, he may himself get very depressed. The pair of them are caught in a vortex of impending loss. They know the inevitable outcome will be the death of the one and the institutionalisation of the other, but they can do nothing to change the approaching situation.

Sometimes a temporary breakdown in health gives a forecast of the future. Seventy-year-old Mrs Porter had looked after her Down's syndrome son on her own since she had been widowed ten years previously. Then she had to go into hospital for an operation. As she had no relations to look after her thirty-year-old son while she was in hospital, the social services department arranged for him to go temporarily into the local mental handicap hospital. She took him to the mental handicap hospital admission ward herself, and, as she was leaving his ward, she heard the male nurse say: 'Let's put this one in the old men's ward, he won't get pushed around there so much, these fellows from home are usually a bit soft and can't stick up for themselves.'

That casual remark was not meant to be heard by the mother, nor was it meant to be unkind; in fact, it showed a rough concern for the quiet retarded man who was dressed so smartly and had obviously led a very sheltered life at home. But those unfortunate words were the last link with her son before Mrs Porter had to undergo her operation. She knew that he would remain in that hospital if she did not get better, for there was nowhere else for him.

Family crisis often results in the unplanned admission to hospital of a physically handicapped person. The above highlights the stresses for both the handicapped person and the family.

Identify ways in which disabled people can remain in their own homes even during periods of stress and consider in particular:-

providing care attendants in the home
providing short term care

What sort of help and preparation should be given to parents when planning for the future of their hadicapped children.

extract from Holes in the Welfare Net

A housing problem

Mr and Mrs Barton's fourteen-year-old daughter, Jean, disabled by arthritis, was living in hospital because her family had a serious housing problem.

The family had a two-roomed flat at the top of a tall tenement house. There were six steps up to the front door from the road, and, on the rare occasions when Jean had a weekend at home, there was no chance of her going out because she was too heavy to keep carrying up and down the steps, so, once home, she stayed indoors for the whole weekend. The lavatory had three steps down into it, so she used a commode in the bedroom. There were three other sisters in the family, and one brother. When Jean had her weekends at home, she slept with her three sisters in the one bedroom, mother slept on the settee, and father and brother shared a bed in the kitchen-living room.

Jean needed a warm bath twice a day, to ease the stiffness in her joints, but there were thirty stairs up to the one bathroom (which was shared with two other families). It was impossible to carry her up the narrow staircase so the family bought a large tin bath, and when she was at home they put it in front of the gas fire in the living-room, and filled it with buckets from the Ascot water heater. The family's attempts to give Jean this necessary treatment to ease her condition were thwarted by the fact that the tin bath was too short for her to lie fully stretched out in, so she could not do the gentle exercises that she was supposed to while submerging her body in the water.

Had Jean's parents been wealthy, with a roomy, centrally-heated house, and adequate bathing and sleeping accommodation, she could have left hospital immediately, but her parents were very poor and had little hope of getting better housing so she would stay in hospital indefinitely.

Jean's parents felt that they were slowly sinking under their problem, since their appeals to the housing department met with total failure. An answer to one of their many letters which had asked for at least a *promise* of re-housing was: 'We cannot take on any more work'. This ambiguous answer might have meant that the local authority could not take on any more building, or that they were not even putting the family on to their already over-loaded housing list. Whatever the answer meant, the result was the splitting up of a family and the unnecessary hospitalisation of an intelligent disabled adolescent who should have been taking her place in family and community life. The hospital was pleasant enough. There was a small school attached to the ward and Jean had friends there, but it was nevertheless very much a hospital, where she faced long hours of boredom, little privacy, and where she was completely cut off from ordinary life.

What action would you take to help Jean and her family?

Apart from the housing aspect, what other help should Jean have been receiving in regard to her long term future prospects?

Relate the above story to your own local authority or health district and consider whether it would be possible for this to happen in your area. If not, why not? If so, then why?

extract from Holes in the Welfare Net

It is not surprising if parents have a lasting resentment about lack of advice. Some said that their children were five years old before they heard about the skilled help they might have been receiving from the voluntary societies for handicapped children, and they wished that their doctors or the hospitals could have put them in touch with the National Society for Mentally Handicapped Children, or the Spastics Society, or similar organisations relevant to their child's particular disabilities, as soon as the baby had been diagnosed as handicapped. Some parents said they never received any advice from the local authority social services departments until their children were seven or eight years old. In particular, the peculiar way in which their children's handicaps were explained to them, and the odd phrases used by the doctors, stuck in their minds and worried them for years.

The rehabilitation of physically disabled adolescents who have spent most of their childhood in hospital is a neglected field. Angela, an intelligent sixteen-year-old, had lived for many years in hospitals. She said that she had no idea what sort of work she could do. 'Perhaps a telephonist or something. But, I'd like to get married first. It's not fair, if disabled people fall in love and want babies they are thought disgusting, aren't they?' Her remarks showed her lack of advice about employment opportunities and the possibilities of normal love and marriage for a disabled woman.

Keeping to the rules

Although most local authorities *are* providing helpful services for physically and mentally handicapped people who live at home, their services are often only available on terms dictated by individual officials who have preconceived ideas about how handicapped people should behave. There is still a widely held belief that disabled people are either 'wonderful' or 'stupid', and those who deviate from this popular image and want to be just themselves are considered awkward and embarrassing.

Look at the above statements and then identify ways in which lines of communication between health and social services departments, and voluntary organisations could be strengthened to help physically handicapped people.

In hospitals is there a need for a specialist adviser to help handicapped people and take on a watching brief when disability is diagnosed?

What is the role of staff in outpatients departments, or on wards, in the provision of information?

Is the confidentiality bar used to avoid providing adequate information?

How far do personalities affect communication?

What can we do personally to help heal personality conflicts between professionals that are liable to harm the happiness of disabled persons and their families?