LIVING IN UNITS
FOR
YOUNG DISABLED PEOPLE

Practical suggestions

King's Fund Centre
1979

Since 1975, a series of study days have been held at the King's Fund Centre to explore the problems of life in residential units for young disabled people. A common theme at these meetings was the isolation felt by both residents and staff. Discussion indicated some similarity in the issues being identified in different units and pointed to possible benefits from a wider sharing of experiences among those involved.

The purpose of this paper therefore, is to make ideas raised at the study days available for critical examination by others concerned with life in residential units as a contribution to further efforts to improve the quality of life in residential care.

The Fund is grateful to Pat Gordon for preparing this summary of the problems explored during the study days and the responses to these problems which have been found useful in current experience.

The Fund is also grateful to Bernard Brett for his personal account of experiences in residential care.

CONTENTS

Page

LIVING IN A UNIT FOR YOUNG DISABLED PEOPLE

A. WHAT KIND OF CARE? 1

B. DESIGNING AND PLANNING A UNIT 3

C. STAFFING 5

D. LIVING IN A UNIT 8

A DISABLED UNIT FROM THE INSIDE: A CONSUMER'S VIEW 11

APPENDIX: A CHECKLIST OF SOME QUESTIONS FOR THOSE RESPONSIBLE FOR YOUNG DISABLED UNITS 19

SUGGESTED READING LIST 20

A FEW PERIODICALS 21

(i) LIVING IN A UNIT FOR YOUNG DISABLED PEOPLE

A. WHAT KIND OF CARE?

1. In an ideal world there would be as much variety of accommodation for disabled people as for anyone else. There would be enough flexibility to allow people with progressive illness to move from self-care to assisted care to full nursing care. Others, as they learned to come to terms with their disability, would move from high dependency to skilled self-care and independence. As it is, however, the disabled person's home is more likely to depend on chance and availability than any assessment of his needs or capabilities. Yet the place where he lives is his home, whether he chooses it or not, and somehow has to provide the security and privacy and independence we all expect in our own homes.

2. Disabled people want to remain part of the community and have access to shops, pubs, libraries and jobs. Some may need considerable assistance with aids to daily living but on the whole they do not want to enter residential care unless it is absolutely necessary. Many more disabled people would be able to manage in their own homes if they had access to the full range of electronic equipment which is now available and also had adequate domicillary support services. Local authorities have the power to pay for alterations and equipment but, in practice, there are long waiting lists for this service. All too often disabled people are moved into residential accommodation, not because their disability merits it, but because their family can no longer cope at home without better equipment and daily assistance. How much of the money spent on residential units would be better spent on equipment and additional support services?

3. An independent life, either alone or with family or friend, is seldom achieved without a struggle. In addition to finding suitable accommodation there are major financial and social hurdles. For example, the disabled person is often at home alone all day while others are at work. Better access to day centres, colleges, libraries, art galleries and other forms of stimulation are urgently needed. The answer may lie simply in organising transport.

4. Group housing projects with a warden and care assistants can solve some of these problems of isolation. They are not suitable for everyone, of course, and one of the main criticisms of group housing is that people find themselves too cut off from the ordinary world.

5. Even if it were possible, not all disabled people would choose to live at home. Residential units can encourage much more independence and be less protective than some familites will ever allow. Unfortunately, people are often admitted to units, and particularly hospital units, because there is nowhere else for them to go, not because they need these particular services. Admission to a younger disabled unit can be traumatic, particularly if caused by family stress or the death of the tending relative or rejection by a voluntary home. The closer the links between hospital, local authority and voluntary units, community nursing services and social services the better. If progressive care can be planned and disabled people can get to know the residential homes and hospital unit in their neighbourhood there is less likelyto be a sense of rejection and isolation if they have to be admitted. This is just one aspect of the need for effective coordination among all the agencies providing care locally.

6. Admission policies are important if units are to function well and not just be used to mop up the problems no one else wants. One suggestion is that all new residents be asked to complete a questionnaire on their normal functioning and special requirements. This might be particularly helpful to those with speech defects. Admission policies also have to take into account the age and ability of residents. Units tend to be aimed at the 16-64 age group but what happens when a long-standing resident reaches the age of 65? Is she to be removed automatically to accommodation for the elderly? Should Hospital Units cater for all disabilities or should they admit only the most severly disabled? What is to happen to those with progressive disability?

7. Hospitals are not the ideal place to make a home. The legal, administrative and organisational framework of a hospital is not geared to home life. On top of this, so many of our hospitals have old buildings and inadequate equipment. 'Making-do' can be very demoralising and frustrating for staff as well as residents. When younger disabled units are set up in hospitals their success or failure has as much to do with the energy and ideas of staff and residents as with bricks and mortar of the building.

B. DESIGNING AND PLANNING A UNIT

1. Neither staff nor residents want to be isolated. The nearer the unit is to shops, pubs, public transport and everyday life the more 'normal' life is likely to be.

2. Units should be small. The right size is probably about 20-35 places. This allows residents a choice of companions but is still small enough to be manageable as a home. It can also be run fairly economically. Some of the places must be kept for disabled people who need temporary accommodation while their families are on holiday or need a break for other reasons.

3. It is vital that all members of the care team as well as a disabled person have a say in the design of a unit but it may be a bigger struggle than you think to achieve this. In one hospital unit, for example, the nurses succeeded in convincing senior staff of design faults only be getting into wheelchairs and demonstrating that the telephone was out of reach. In another, the architect was persuaded of the problems of his design only after the nurses had taken him to the loo in a wheelchair. Even after plans have been passed it is important that those who will live and work in the unit are consulted before any changes are contemplated. What appear to be small design faults can assume enormous proportions when you have to live with them, so prompt and perhaps unconventional action is often needed to avoid frustrations later.

4. It does not seem to matter whether the unit has to be fitted into existing accommodation or is a new "package deal", the same old mistakes seem to be repeated. Windows are placed too high for people in wheelchairs to see through. French windows are too narrow to take a hospital bed and so constitute a fire risk. Surgeon's sinks without plugs are installed in bedrooms. Front doors have no bells. A greenhouse specially for residents has doors too narrow for wheelchairs to pass through. These are the kind of mistakes that still seem to be made by planners although they are so obvious to a disabled person or experienced staff. One of the most common reasons for units being under-occupied is bad design.

5. A kitchen is absolutely essential in all units and must be planned and equipped to allow residents to cook for themselves and their friends. Long stay residents get very, very bored with the same, predictable food from central kitchens.

6. There must be more than one public room. A dining room which has to double as a sitting room is quite inadequate. Flexible space is needed to allow various activities to take place at the same time and to allow men and women to mix or not, as they choose, in public and in private. Residents must also have somewhere congenial to entertain family or friends. Informal conversation areas where people can sit and chat or just watch the world go by are invaluable.

7. An 'interview' room is a good idea. It is somewhere, not a bedroom or sitting room, where residents can talk in private to their lawyer, or adviser, or family friend.

8. A mix of single and double bedrooms is needed with locks and keys, and an alarm call system which works.

C. STAFFING

1. Working in a residential home is very different from working in an ordinary hospital ward. The pace of life is much slower. Events and circumstances change only gradually. The same group of residents are around for a long time. The work is extremely taxing, both physically and mentally for staff of all disciplines. Heavy patients have to be lifted and supported several times a day. Others have to be fed and this can take 1½ hours each meal time. Senior staff sometimes fail to recognise that in addition to nursing and care duties, staff need time to sit and talk and to listen to patients. An adequate staffing ratio of at least 1:1 is essential for an active rehabilitative programme and to allow time for caring for all the needs of the disabled person.

2. There are often particular problems in staffing units. It is not uncommon for units designed for 28 people to be permanently under-occupied because of staff shortages. Recruitment of trained staff is one problem but it may be that only a modicum of trained staff is needed as long as there are well-selected untrained staff who receive good in-service training and support. Care staff is a good name to cover all those who work in young disabled units. One unit ran a successful recruitment programme which attracted married women and young people. Many of the young people intended going on to medical or para-medical careers and stayed on the unit for 3-12 months.

3. Another idea for maintaining adequate staffing levels in hospital units was to rotate all staff at 3 monthly intervals to different hospital wards. It was felt that this avoided too much strain on the younger disabled unit staff and allowed them to return refreshed after a break. Other units believe that constant staff changes are not a good thing. In one unit, prospective new staff are always shown around by an experienced resident who has become a very useful member of the staff selection team.

4. Nursing staff trained in a general hospital may find it particularly hard to adjust to the pace of a unit which attempts to adopt a more informal approach. Newly trained staff have been found to become more easily discouraged than more experienced staff. Older married women can be an important part of the care team. The slow pace seems to lead to occasional bouts of low staff morale but if this is recognised support can be provided in working through these periods.

5. A great deal depends on the person in charge of the unit. Wherever it may be, it is a lonely job. It must be recognised that special training is needed to develop leadership skills and to learn to overcome the problems of institutionalisation and over-dependency of the long-term resident.

6. Early induction courses are essential for all staff and should include a talk by a disabled person. The best training of all is to ask new staff to become disabled for a day - to be confined in a wheelchair, to be fed and put to bed and toileted, to ride in a bath hoist. This will bring home the fears and frustrations of disabled people more powerfully than any number of lectures.

7. From the very beginning all staff must be taught to respect the privacy of every person in a residential unit.

8. Nurses who are not used to disabled people often find it difficult to approach them as individuals with similar emotions and needs as themselves. It is incredibly depressing always to be talked down to in an artificially cheerful manner. Staff have to learn from residents. All disabilities are different and highly individual. There is no correct way of doing things for everyone and disabled people are often expert at knowing the best way of handling their own disability. Trained staff who are used to telling people what to do, don't always find it easy to learn from residents.

9. Regular staff meetings are essential to nurture the teamwork approach and to provide support and guidance to all members of staff.

10. Staff in residential units often feel isolated. Local or regional meetings to exchange experiences and learn from each other can be very helpful, especially if staff from voluntary organisations and local authority units are included as well as NHS units. Isolation within the hospital is also common. Misunderstandings occur and even hostility from other ward staff, especially if the unit has a "relaxed" policy. It always pays to invite other staff to see round the unit and learn how and why it works.

11. As well as barriers between hospital departments, staff may also have to work hard at breaking down barriers between themselves and their disabled residents. There is often a tendency to adopt a role which encourages dependency. Disabled people themselves create barriers. Those brought up in institutions, for example, may look on staff as authority figures and be very reluctant to allow them to relinquish that role and to make decisions themselves. Uniforms and badges can also create barriers. Unfortunately, management rules all too often restrict such freedom as residents can and should enjoy.

12. Staff need much more support in recognising and dealing with residents' emotional needs. It is very easy to concentrate on physical care alone.

13. Initiative is essential if residential care is to be successful. Enterprising staff have got to be encouraged even if this does involve some risk-taking and bending of rules. It will almost certainly involve staff in activities outside their normal duties. Above all, the aim for both staff and residents must be to remain as close as possible to the pattern of ordinary, daily living. Many good staff have moved on to other fields through sheer frustration of not even being allowed to suggest good ideas, let alone put them into practice.

D. LIVING IN A UNIT

1. Those who live in young disabled units are adults. They are not sick people or over-grown children. They live in units not because they need treatment but because they need help with the physical aspects of daily life. But physical dependency does not mean they must relinquish control over all aspects of their life and environments.

2. Few people want to be passive receivers all their lives. Disabled people who live in Younger Disabled Units are no different. They must be allowed a sense of responsibility towards their home and towards its staff. They must be allowed to contribute what they can and to achieve a sense of satisfaction. If the disability is such that, for example, making the bed would take all morning, then this is obviously not a realistic contribution; but acting as telephonist might be, or book-keeper for pensions and benefits, or window-box gardener or transport organiser. How many staff know what their residents' jobs were before they became disabled? If all the opportunities are exploited a unit can offer more in the way of activity and participation than an isolated home life. It may be hard for staff to encourage residents as they will often find it easier and quicker to do things themselves. But busy nurses and bored residents don't make for much of a home life.

3. Regular meetings between staff and residents have been tried in most Younger Disabled Units. Some seem to work better than others. One of the most successful evolved from a formal meeting into an informal understanding that everyone got together each day for half an hour before lunch. This became a kind of family gathering when information could be exchanged, gossip passed on or problems aired.

4. "I almost go crazy with boredom". This comment expresses very clearly the frustration felt by a disabled resident. Boredom leads to friction among residents and between residents and staff. But it is not solved by just providing something to do, regardless of previous interests and skills. Employment, for example, must be a matter of choice but if a resident wants to work staff must do all they can to make this possible, even if it involves taking risks. Disabled people are often encouraged to take the easy way out and not to experiment and discover how much they could achieve.

But by the same token those who do not want to work must not be forced into routine, money-making activities. Learning to use a printing press or a knitting machine is likely to be more worthwhile and absorbing than packing matchboxes.

5. Boredom is also lessened if residents are encouraged to take an interest in others. One unit adopted a child in India and spent a lot of time and energy raising money for her welfare. In another unit the residents regularly run parties for the staff's children. The arrival of a dog and a cat created new interests in one unit. A holiday exchange scheme with a Younger Disabled Unit in Bordeaux was successful in another.

"When I go home for the weekend I feel as though I have come out of prison and am returning to civilisation. I can go to the pub or the betting shop". As is only too clear from this comment, maintaining links with the "real world" is one of the most crucial of all aspects of life in a residential unit. Disability and communal living may severely limit freedom of choice, but what there is must be exploited to the full.

7. Alcohol can sometimes be a problem in residential units. One unit which had difficulties with residents getting drunk in their own rooms decided to open a bar at lunch time and in the evenings. It was a great success, and improved relationships all round.

8. Disabled people have to live a rather public life because of their dependency. This makes it all the more important to preserve whatever privacy is possible. Personal affairs must not become public property. Casenotes must be handled with discretion - are they to be available to all staff? Is there a clearly understood policy on confidentiality? Privacy also means a place to call one's own where normal domestic clutter is not frowned on. It means sound-proofed rooms. It means locks and keys which are the property of the resident.

9. Privacy also means the opportunity for men and women to meet and enjoy each other's company without subterfuge. Sexuality is as much a part of the disabled person as anyone else but there is often an official silence on the subject in residential

units. Simple practical matters have to be sorted out. Are there double beds, for example? Are there "Do not disturb" notices which are respected? Are there locks on the doors? Is there a good alarm-call system? Above all, is there respect for privacy?

Disablement can lead to particular sexual difficulties such as inability to take up sexual positions and fears about physical comfort and pain. Some disabled people need factual information on sexual activities, which is often lacking especially if they were brought up in an institution without normal growing-up contacts. Contraceptive advice and genetic counselling may also be necessary. Couples planning to leave a residential unit and set up home together have benefited from an assessment unit which alows them to explore the sexual as well as practical aspects of living together.

10. Too often staff are left without any guidance on how to help and advise residents on sexual matters. It is not an easy subject in a residential unit. Some units have introduced counselling sessions to encourage staff to discuss the matter openly and explore their own feelings about it. These have been very successful and have helped to tackle sensitive issues such as the disabled person's need for help with intercourse or masturbation- the sexual needs of the disabled person's husband or wife; parenthood- homosexuality. Another benefit of these sessions has been to make sure staff know about specialised help which is available and when to use it, such as the Family Planning Association and Marriage Guidance Council, Sexual Problems of the Disabled.

11. Adults normally take risks. Perhaps the most important lesson for those running Younger Disabled Units is to enable their residents to take risks, to "live dangerously". In a residential unit it is not easy but it is vital if life is to be worth living.

Pat Gordon

A DISABLED UNIT FROM THE INSIDE-A CONSUMERS VIEW

Presented by Bernard Brett

As a severely disabled person I have watched with interest the development of Hospital Units for the Younger Disabled, following the passing of the Chronic Sick and Disabled Persons Act 1970. So when I had the opportunity to do a MA course in Social Policy and Administration at Essex University, I decided to do my research project on how these Units were set up and how they are functioning now.

The methods of research which I used were a fairly full questionnaire for both the residents and the staff, together with the technique of participant observation. To this end I stayed in a number of these Units so I could get a first hand impression of what life was like.

I am fortunate in being able to live in my own home and am able to take a fairly full part in certain activities within the community of a town, including being Executive Secretary of a Housing Association which caters for homeless families and their children, which has been my main work during the last ten years. I also help run a branch of the Disablement Income Group and am on its National Executive Committee. I feel deeply the need to try and help severely disabled persons to live as full and interesting a life as possible, whether they reside in the community, residential homes or in hospital. This is mainly why I have done this research project on Hospital Units for the Younger Disabled, because I am sure this provision is intensely important for those handicapped persons who are forced to use them.

There were revealing differences between the units which I visited and studied. As it happened the buildings were almost identical in their design and layout, but in certain ways their atmospheres were contrasting. For instance, one was run very much as just another ward in a hospital and a resident told me that it was only after he had been living there six months, that he realised from an envelope addressed to him by his solicitor, that he was in the Young Chronic Sick Unit. This came to him as quite a shock. On this unit nearly all the women residents were put to bed between tea at three o'clock and supper at six, which made for an extremely long and boring evening for them. There were few opportunities on this unit for the residents to follow any activities. Those who were not confined to bed, were brought into the day-room before breakfast by the departing night staff and parked round the outer walls of the room, without any table or other amenity within reach. On two mornings a week a part-time OT came and tried to help a few of the residents to throw bean bags, through holes cut in a wooden board, which at least provided the chance for a little banter. Only two of the residents out of sixteen were at all mobile thanks to their electric chairs, while the other patients had to sit where they were parked all day long. "I almost go crazy with boredom", was how one resident expressed it. The most common activity for many of the patients was sitting slumped in the rather un-yielding hospital chairs, dozing (or pretending to do so) in an attempt to pass the time away. One active former printer aged 40, suffering from multiple sclerosis remarked, "I sit dreaming of my comfortable arm-chair which was sold up with my flat, I wanted to ask whether I could bring it here, but I didn't like to as this is a hospital". This same resident said that when he wanted to lie on his adjustable bed for a rest, which he still could do himself, he found that the nurses who had made it, had left it at its full height where he could not reach, despite his requests and even notes, asking for the bed to be left in the lowered position. These are two small examples of where life could have been made easier and better for this resident if more imagination had been shown in the running of the unit. Staff have to be shown by their superiors that the comfort and convenience of a long term resident is more important than having all the beds made up in the same way.

This reflects one of the great difficulties of these hospital units for the Younger Disabled. They are supposed to be as home-like as possible, but because they are situated and managed within a hospital they tend to conform to the functioning of the way that organisation works. This makes for many headaches for the charge-nurses or sisters who are trying to run these units because they feel criticised and unconventional if their units are run differently from other wards in too many ways. It is vital that senior nursing officers and administrators give the people in charge of the units all the support they can to develop the individual care and identity which should be a special feature of these units. The position of charge-nurse or sisters trying to run and organise these units is a lonely one, particularly if they are trying to break new ground or trying to cope with the clash of personalities either between residents or among members of the staff.

All too often the sister or charge-nurse feels that their superiors expect them to do a very difficult job without providing the means or the resources to carry them out. This is of course the case in all branches of the hospital service but these units being still in an experimental stage, the uncertainities and strains on senior staff may be more accute.

This is also a quite different type of nursing from that practised in medical or surgical ward. Instead of the treatment being the main reason for the residents being there, it is instead the quality of the severely disabled persons life, which may be seen as the goal of these units. This means providing care and nursing, which should give the back-ground for enabling the disabled person to lead as full a life as is possible within his limitations. This is a rather idealistic view, which corresponds to the "Horticultural Model" in Miller & Gwynne's study of Residential Care for Chronic Sick Patients - "A Life Apart". In reality, the position of many residents in units for the Younger Disabled is closer to the concept of the "Warehousing Model", also from Miller & Gwynne. This sees the object of these units as being to provide sufficient physical care and attention to maintain life, while gradually reducing the area of social contact and activity until the residents are socially dead, while they wait for physical death to over-take them.

Another important difference between these units and other hospital wards is that the techniques of nursing and care are not the same. The residents tend to have been disabled for quite a long time and have become rather set in their ways as well as developing methods of care which suit them best. One reason why many handicapped persons prefer not to be looked after by members of the nursing profession, is that we prefer to train our helpers into our own ways, rather than being told that we are doing everything all wrong and "this is the right way". This attitude towards personal care can be especially annoying if one has had to live with and come to terms with one's disability over many years.

One of the most difficult things for residents and staff to try and sort out in these units is the balance between enabling the patients to retain some independence and freedom while living within the hospital culture. Nurses and doctors are used to having a great deal of authority over the patients, while they are being treated, so there is a tendence for this to spill over into the Younger Disabled Units too. For instance, a resident told me that he had been informed that he was not to leave the unit in his wheel-chair because he was the responsibility of the hospital. This really brought home to this resident how restricted his freedom had become. In other units residents were not allowed to go out in the evening with friends or relations, even when they made arrangements to be put to bed. Such opportunities to go out in the evening can be especially important to those disabled persons who have had a full social life before being admitted to the unit. One good evening out with friends or relations can help to give a spice to life and can assist in retaining social contacts.

Ways to encourage residents to retain or develop links with the outside community seem very important. There seems to be a considerable diversity between practises in different units. On one hospital unit, which I visited, they had had one trip out with the residents during the previous nine months, while on another which had access to transport, they had trips out at least once a week and sometimes more often. In my view the provision of adequate transport, together with drivers for these units (as also for some geriatric wards) should be one of the priorities for helping staff and residents towards a better and more interesting life for those living on the units. It saddened me to watch fleets of vans passing the door of the unit each day either carrying one or two nurses or a few laboratory samples, while there was no transport for long stay patients who needed stimulation and a change of scene. These hospital vans could not be used for patients, because of questions of insurance, and job specifications for drivers which are undoubtedly serious matters but these could surely be ironed out, even if this meant going to the highest authority and the unions. Alternatively, District Management teams should be more willing to hire specially adapted vehicles from the community when these were required and should be willing to pay members of the staff to drive in their working hours. In many cases today, if a nurse wants to drive some residents out he has to do so in his off duty time because he would be breaking the hospital regulations by doing so in his working hours. This is an example of iniatives made by the staff which could enrich the lives of many residents in the units but which can be discouraged or stopped through the working of red tape.

With residents who have become institutionalised over many years or who have progressive diseases, there is often an unwillingness to make the effort to go out, meet people or do anything new. This is a vicious circle which needs careful handling but can respond to sensitive if firm leadership perhaps with the help of more active residents. I am sure there is nothing to be gained from forcing residents to go out if this is not what they want, but from my personal experience I believe firm encouragement to attempt something new can be very helpful if the person concerned can feel that it is he who is making the decision rather than having it imposed on him.

In my research I observed that although spouses and close relatives do tend to show very considerable loyalty to those living in the units, other friends quickly drop away. Out of the sample only 10% of the residents said they received visitors from outside the hospital. It was apparent that once a person was admitted to the units most of their former friends stopped coming to see them. This greatly increased the isolation and feelings of deprivation which were common among the residents.

Despite the fact that visiting hours were formally flexible, a common feature of units where I visited was that little attempt was made to make those visitors who did come feel welcome, either by the residents or the staff. Visitors are the lifeblood for bringing new contact and support for the residents, it is important that when they arrive, they feel wanted rather than feeling like intruders as is sometimes the case. The residents themselves could well be encouraged to take a more active role as hosts in their own best interests. Greater involvement of relatives and visitors in the life of the units seems of the greatest importance, which can only be done if nurses and domestics are helped to see them as part of the whole team seeking to improve the quality of life on the units. I would like to see more meetings experimented with between relatives, friends, visitors, staff and residents, maybe over a drink or some refreshments, to promote the common interests of the units. This will obviously be more successful in some places than in others, but there is plenty of evidence to show that people are more willing to help if they feel involved and part of a team.

One of the most common feelings among the residents was that they had no control either over their own lives or of the environment in which they spent their days. As one resident expressed it, "When I go home for the weekend I feel as though I have come out of prison and am returning to civilisation. I can go to the pub or the betting shop." For people who have only recently become disabled the experience of being admitted to a hospital unit for the Younger Disabled is especially traumatic. Not only are they removed from their families and friends, but several of the people I interviewed had signed over their pensions to relatives and given their solicitors a power of attorney, almost as if they were assuming that they had no longer a role in the community. This attitude is understandable but requires to be actively countered by doctors, administrators and members of staff. However, the very position of these units within hospitals makes it even more difficult for residents and staff to have a real say in the daily running of the units. Administrators and senior nursing staff should be more willing to give the maximum opportunity for a team to be set up on the unit made up of the nurses, the residents, domestics and also the doctors, physiotherapists and occupational therapists, who can discuss ways of developing new activities for the residents, widening social contacts and generally improving communications. There are also questions of how the residents and the staff feel that they are being treated by each other, which may need discussion and airing too. This can present many difficulties, especially where there are clashes of personality but where there are people completely dependent on others this frankness within the group can be healthy and helpful.

It seems important that more special training courses are provided for sisters or whoever is in charge of these units, to give them wider understanding of the problems confronting the severely disabled residents and how they can be assisted to over-come the dangers of institutionalisation and over-dependency. It may also be good if they are helped to learn how to handle the strange ways of unit administrators and senior nursing officers. The development and deepening of leadership skills seem to be especially important because so much depends on the way the person in charge of the unit manages it. The sister needs to be a person who can inspire confidence and flexibility in the residents and the staff to break out from some of the ruts which they can too easily get into. For instance nurses who have not before worked with handicapped people often treat them as children, even when they are not.

One reason for this may be that they wish to retain a distance between themselves and persons who they want to stress are totally different from themselves. This can become incredibly depressing and frustrating for the disabled person if he or she has constantly to put up with being talked down to in an artificially cheerful manner. The number of doctors and nurses who still talk about patients while they are with them is still surprisingly high, as though the handicapped person was an object of care, rather than a human individual.

The special training for persons who have been appointed to be in charge of hospital units for the Younger Disabled should not merely be short day or week courses, but should cover a wide range of subjects including community care of the disabled in their own homes and study rehabilitation techniques from this and other countries. It might also be helpful if members of staff were given some first hand experiences of what life was like if they had to use wheel-chairs or indeed hydraulic lifts too. Selection of staff and particularly sisters in charge is very important. Unfortunately the range of candidates for these posts tends to be limited especially now that the novelty attraction of these units has dimmed and they are seen to cater for mainly late middle-aged handicapped persons, not young disabled men and women, as was first assumed.

This brings me to one of my deep felt beliefs, that where possible in future units for the severely disabled who require considerable care and attention should be built in the community rather than within hospitals because this would enable the staff and residents to remain closer to the pattern of daily life within a town or village. It would be easier to develop links with groups and families within the area because a large section of the public are scared of visiting hospitals although this does apply to a lesser extent to other kinds of residential centres.

In conclusion, it may be useful if I tell you someting about myself. I was born in Belfast forty-two years ago, a sufferer from cerebral palsy and having the use of one hand only. I have never been able to walk or speak, nor have I been to school. As a small child when my parents took me to be seen by a Harley Street specialist, he told them that I would grow up an idiot and strongly recommended that I be sent to a mental subnormality hospital. Luckily for me my parents thought they saw a lively twinkle in my eyes and decided to keep me at home. My father who was a solicitor took three years to teach me to read and write after returning from his days work in the office. Later in my teens I was an avid reader, thanks to the stimulation and friendship of under-graduates from the local University who came to tutor me. For the first twenty-one years I lived a very cut-off and protected life with my parents, partly because my feeding difficulties made my mother believe that only she could keep me alive or look after me which made me far too dependent. So when I was twenty-one I welcomed the opportunity of coming to a residential centre for adult spastics in Essex because I realised that unless I got away from my parents I could never hope to develop my personality or whatever gifts I had. The seven years I spent in this residential centre were the best and most useful experiences of my life because I learnt a great deal about mixing with people, accepting and being accepted as well as coming to realise that I was a person who could love and be loved. I was fortunate that the Warden was a remarkable and enlightened man who encouraged the residents to try and be as enterprising as possible even if it involved taking risks and involving members of the staff in activities outside their normal duties.

In 1964 I was able to move into a house in walking distance of the town centre of Colchester. I could not have made this move without the help of a young girl working at the residential centre who assisted in getting me established together with financial support from my family. I found life became infinitely more interesting, stimulating and varied thanks to living in the community, instead of being cut-off in a residential centre in the country a mile up a drive. I helped to start and am still Secretary of a Christian Action Housing Association which provides homes for homeless families and others with special needs such as single-parent families, ex-prisoners and other socially handicapped groups. This has been intensely interesting work for me because each year I see hundreds of people in severe housing difficulties who would never think of coming to talk with a severely disabled person in the ordinary way. Also it has meant I have built up a wide network of contacts in local government.

APPENDIX: A CHECKLIST OF SOME QUESTIONS FOR THOSE RESPONSIBLE FOR YOUNG DISABLED UNITS

1. Does the unit maintain good links with the community services ?
2. Are there good links with the community nursing services?
3. Does it offer holiday admissions to disabled people living at home on a regular basis, not just once a year?
4. Does the unit help provide a 24 hour emergency service for families in a crisis?
5. Are residents able to go home for weekends and holidays with sufficient support and aids?
6. Are those previously used to looking after themselves at home allowed to manage their own medication?
7. Are residents able to cook for themselves and entertain friends?
8. Are visitors positively welcomed?
9. Are residents with varying disabilities encouraged to help each other?
10. Are those who are able, allowed to rise late in the morning if they choose to stay up to watch the midnight movie?
11. Do disabled people face long empty evenings having been put to bed at 6 p.m. ?
12. Are they dressed in the morning by the night staff and deposited around the walls of the day room?
13. Does their daily routine revolve around feeding, sleeping, and toileting (like a baby)?
14. Is there somewhere congenial to talk, to have a drink and relax?
15. Are there easily accessible telephones?
16. Are there regular newspapers and magazines?
17. Is there easy access to public libraries and to further education colleges?
18. Could classes be held in the unit?
19. Is there adequate transport and drivers?
20. Could transport be hired from the Social Services Department or a voluntary organisation?
21. Can staff be paid to act as drivers in their spare time?
22. Could 'out of hours' use be made of hospital vans which at other times carry lab specimens?
23. Are staff encouraged to listen and learn from residents and are administration staff available to give support and encouragement to unit staff.

SUGGESTED READING LIST

A Life Apart, E. J. Miller and G. V. Gwynne, Tavistock Publications, 11 New Fetter Lane, London, EC4P 4EL

An ABC of Services and General Information for Disabled People by Barbara Macmorland, London, Disablement Income Group, 1976

Coping with Disablement by Peggy Jay, London, Consumers Association, revised edition 1976

Designing for the Disabled by Selwyn Goldsmith, 3rd edition, London, Royal Institute of British Architects, 1976

Directory for the Disabled, compiled by Ann Darnbrough and Derek Kinrade, Woodhead-Faulkner, Cambridge, 1977

Disability Rights Handbook for 1978, London, Disability Alliance, 1978

Entitled to Love by Wendy Greengross, National Marriage Guidance Council, Little Church Street, Rugby

Equipment for the Disabled, 3rd edition (in ten sections), compiled by Mary Marlborough Lodge, and available from 2 Foredown Drive, Portslade, Sussex BN4 2BB (Sections 1-4 now in 4th edition)

Guide to the Social Services, 66th edition, London, Family Welfare Association, 1978

Handbook of Housing for Disabled People by John Penton, London, London Housing Consortium 1971

Handicapped at Home by Sydney Foott, London, Design Council, 1977

Help for Handicapped People, prepared by the Department of Health and Social Security and the Welsh Office, 1975

Help Starts Here by Philippa Russell, London, National Children's Bureau, 1977

Home Made Aids for Handicapped People, revised edition, London, British Red Cross Society, 1974

Incontinence, Dorothy Mandelstam, The Disabled Living Foundation, 346 Kensington High Street, London, W.14

Living in Hospital 100 Questions, The King's Fund Centre, 126 Albert Street, London, NW1 7NF

Rehabilitation, Retraining, Resettlement, Employment Services for Handicapped People, Employment Services Agency and Central Office of Information, London, HMSO, 1976

Self-help and the Patient, organisations concerned with particular diseases and handicaps, 5th edition, Patient's Association, 11 Dartmouth Street, London, SW1 9BN, 1976

So You're Paralysed by Bernadette Fallon, Spinal Injuries Association, 126 Albert Street, London, NW1 7NF

A FEW PERIODICALS

ACTION MAGAZINE (quarterly)

National Fund for Research into Crippling Diseases,
Vincent House, Springfield Road, Horsham, Sussex RH12 2AN (£1.70 p.a.)

BRITISH JOURNAL OF OCCUPATIONAL THERAPY (monthly)

British Association of Occupational Therapy,
20 Rede Place, London, W2 4TU (£7.00)

C.C.E.T.S.W. BULLETIN (occasional)

Central Council for Education and Training in Social Work,
Derbyshire House, St. Chad's Street, London, WC1H 8AD (£0.35 each)
Social work education, news and views.

CHESHIRE SMILE (quarterly)

Cheshire Smile,
'Greenacres', 39 Vesey Road, Sutton Coldfield, Warwicks B73 5NR (£0.50 p.a.)
Magazine of the Leonard Cheshire Homes.

CHEST, HEART AND STROKE JOURNAL (quarterly)

Chest, Heart and Stroke Association,
Tavistock House North, London, WC1H 9JE (£1.20 p.a.)
For medical and paramedical professionals.

CONTACT (bi-monthly)

Royal Association for Disability and Rehabilitation,
25 Mortimer Street, London W1N 8AB (£2.50 p.a.)
For the disabled and people working with them

DESIGN FOR SPECIAL NEEDS (three per year)

Centre on Environment for the Handicapped,
126 Albert Street, London NW1 7NF (£5.50 p.a.)

MUSCULAR DYSTROPHY GROUP JOURNAL (quarterly)

Muscular Dystrophy Group,
Nattrass House, 35 Macauley Road, London SW4 0QP
Free but donations requested. Newspaper

REHABILITATION WORLD (quarterly)

20 West 40th St., New York NY 10018 ($10 per year)
U.S. journal of international rehabilitation nes and information

ROYAL ASSOCIATION FOR DISABILITY AND REHABILITATION BULLETIN (monthly)

RADAR,
25 Mortimer Street, London W1N 8AB (£1.25 p.a.)
News, parliament, books, services, conferences

S.P.O.D. INFORMATION SHEET (irregular)

Committee on Sexual Problems of the Disabled,
49 Victoria Street, London SW1H 0EU (£1.25 per year)

GLAD NEWS (quarterly)

Greater London Association for the Disabled,
1 Thorpe Close, London W10 5XL (£1.00 p.a.)

HANDCRAFTS ADVISORY ASSOCIATION FOR THE DISABLED (twice a year)

Handcrafts Advisory Association,
103 Brighton Road, Purley, Surrey CR2 4HD (£2.50 p.a.)
Articles on crafts, information on equipment, new books etc.