

PROJECT 81
ONE STEP UP

Consumer Director Housing and Care for Disabled People.
The experience of three people

PROJECT 81 -ONE STEP ON

This book is dedicated to:

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and

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PROJECT 81 - ONE STEP ON INTRODUCTION & ACKNOWLEDGMENTS

Most severely disabled people live either with their families or in a Residential Home. A few have the good fortune to marry an able-bodied partner who, by taking on the role of un-paid carer, makes a more conventional life-style possible. Fewer still have the wealth to buy care.

Liz, Philip and John were neither married, nor rich, and they were not prepared to commit themselves to a Residential Home for the rest of their lives. They wanted to do what their able-bodied peers took for granted: live ordinary lives, in ordinary houses, in ordinary streets. Their ideas were shared by a number of their fellows, who, throughout their endeavours, supported, encouraged and worked for each other in a group called Project 81.

To achieve these ambitions they pursued orthodox paths: houses from house people; care from care people.

The group set out their intentions in a book published in 1982 called "Project 81- Consumer Directed Housing & Care". Four years have passed since that book was written and Project 81 no longer exists, since all the active participants have achieved their intentions. This book: chronicles, in their own words, the experiences of three of the group.

This is not a "How To Do It" manual, for those details please read the associated HCIL publication: Source Book Toward Independent Living.

The purpose of - this book is to shout loud and clear:

"SEE. WE DID IT! DESPITE EVERYTHING, WE MADE IT. "

The book is a celebration of that fact, and an encouragement to disabled people, showing that when we work together we really can change things. The title, "One Step On" indicates that "moving out" was just a beginning, and recognises that "Staying Out" is another story!

The book is intended for fellow disabled people who alone can imagine the enormity of the struggles hidden in the following pages. To the interested able-bodied reader: Please begin to comprehend the impossible burdens heaped on the heads of some of the most disadvantaged people in our society.

PROJECT 81- ONE STEP ON INTRODUCTION & ACKNOWLEDGMENTS

Some details that may help your understanding:

Le Court is a large residential Home from which a number of the people in Project 81 came. The Home supported their endeavours.

Liz, Philip and John were at Le Court because they required physical assistance with most everyday functions.

This assistance, directed by the individual disabled person, is variously referred to as:

"care", "support", "care support", "aid", "aid to daily living", etc,

and it is supplied by lay people variously called:

"Care Attendant", "Attendant", "carer", "Personal Aid", etc,

some of whom "live-in" the home, or, are "casual" and only come in when required.

We are indebted to Liz, Philip and John for allowing us to share their personal experiences.

And the Leonard Cheshire Foundation whose grant made it possible to catalogue these details.

This book is the last act of Project 81.
The banner is now carried by HCIL.



LIZ

LIZ

MY EARLY YEARS

I had always lived at home with my family. Mum has rheumatoid arthritis and, as neither of us could manage the stairs, we shared the same room downstairs. I started at a nearby Special I School when I was three. Mum looked after me at home.

When I was 16 I gained CSE Grade One English and chose not to accept the only job suggested, packing boxes, and instead tried Further Education. The Technical College was next door to the Special School and I was able to continue attending my old school and go to the 'A' Level English lessons in the College.

At this time I was thinking of a career in writing. I had not thought about much else except that. Unlike many of my friends, I did not want to leave home. I used to be scared of the possibility that one day Mum wouldn't be able to get me up. Even then though, from time to time, things could be difficult.

A TASTE OF RESIDENTIAL CARE

All the way through school, my Mum used to go away for a fortnight's rest during the Summer and I would go and stay in one of the various holiday homes for disabled children.

Soon after I got my English 'A' Level, Mum learned that she had to go into hospital for quite a long time. Her only concern was where I should go while she was away. Mum did all the work of trying to find something.

Being 18, I was too old for many Children's Homes and too young for Adult Residential Homes. Fortunately I was able to go to a Rehabilitation & Assessment Centre for two weeks. Whilst there I was introduced to the nearby Cheshire Home and went there for five weeks. I hated it. For the first time in my life I was made conscious of not being able to control my own situation. All I can remember was that everything was uncomfortable, especially getting up and going to bed. It wasn't like having Mum around.

When Mum came out of hospital I returned home. District Nurses were made available to help Mum look after me, although they were very

unreliable. I began to realise that life like this could not last for ever and so I asked to go back to the Cheshire Home for a holiday. I cannot really remember why. Perhaps I just wanted to go back to find out why I hadn't get on with the place when everyone else had! Anyway, Mum says I was restless when I returned from my second holiday there.

Back at home Mum and I managed with the aid of a Home Help and District Nurses. Mum was more worried about things than I was. I continued studying through a correspondence course with the National Extension College, "Writing For Everyone."

Next Summer Mum was told she would have to go back into hospital for a long time, and because I already knew the place, I agreed to go back to the Cheshire Home for this period. Something went wrong while my Mum was in hospital and I ended up being in the Home for seven months. During this time I began to realise that perhaps I wasn't going to go home. Understandably there were lots of tears. Up until then I had always thought that I would go home, but now I wasn't sure.

During the seven months at the Home I was offered permanent residence but my social worker rejected it because she thought I was going home. Most of the time I too thought the same way.

DIET OF RESIDENTIAL CARE

Then my Mum came out of hospital she was still in plaster and couldn't look after me. Because the Home were planning to cut down their numbers I was asked to find somewhere else to live. I left in the following March, and went to a Local Authority home, for six weeks.

This place just did not have the necessary staff levels for my care. I was classed as heavy care. Apart from having to get up and go to bed at certain times, I was fed up because nearly everyone else spent the day at the Day Centre making baskets and playing Bingo. I did not want to do this and didn't go. The building, the staff and the food were wonderful, but I wasn't allowed out of the front door on my own. I spent my days with a lovely old lady who stayed in bed because the staff didn't have enough time to get her up. Luckily I had friends living locally who came to visit me regularly and I went home every weekend, otherwise I would have gone mad.

I contacted my social worker and told her that I could not stay at this place and that she would have to find me a Cheshire Home. She came

up with the Placement Centre at Heenan House, which was part of the St Joseph's Hospice for the Dying in Hackney. Dr. Agerholme was in charge and she was quite willing to have me there. I moved in and was there for three months. I had a great time. There were lots of young people working there whose main ambition was to get me into a good Home.

During my stay my mother and I went to see Dr. Agerholme. She explained that I could stay at Heenan House until I could find somewhere suitable to live. Then she asked if I would consider returning home with someone living-in to look after me. She explained what this would mean. I don't know what made me, but I felt it would not work in my situation. I knew my Dad would not particularly live a stranger living-in. Also my Mum had to share a bedroom with me and she did not like watching someone else seeing to me. What is more, I was 21 years old now and I had discovered just how much freedom I could have away from home I chose Residential Care and so it was that I came to Le Court in September 1977.

LE COURT

Soon after arriving at Le Court I knew that this was the place for me. I was enjoying myself. I could not get over the fact that people were giving me the responsibility of telling them how to get me up, and that I could choose what time I went to bed I quickly settled in and became increasingly involved in the life of the Home. It was the policy that residents were expected to contribute to the life of, the community.

BEGGINING TO LOOK AROUND

As time passed my feelings towards the Home changed slowly. I wanted to do more for myself. I was going out of the Home more often and people had begun to comment on this. I began to feel a little restricted. There was a growing unrest amongst the younger residents. Some of us resented the level of continual commitment to the Home which was expected of us. Also, none of us wanted to spend the rest of our lives there, even though we did not know what else there could be. I think the arrival of a new resident, John Evans, had begun to focus our restlessness. He was quite determined not to stay in Residential Care.

TAYLOR HOUSE

During 1979 I went to Taylor House for a holiday. Taylor House is a very small Hostel for disabled students. It is an enlarged ordinary house in an ordinary street. The four students and the staff work out the running of the household between them and share the responsibilities. I was so struck with the place that when I came back to Le Court I told John that he ought to go there for a visit .

PROJECT 81

Soon after John came back from Taylor House several of us started meeting together more formally. That was the beginning of Project 81. The idea was that a group of us would move into a big house and have young people as staff helping us. Just like Taylor House. We were encouraged by Ann Parkes who had recently started work as the General Manager of the Cheshire Foundation Housing Association.

For a long time I was not exactly sure what I wanted from Project 81. I just felt I ought to be doing something and so I stuck to it. We were looking for a big house in Southampton.

In the Summer of 1980 a suitable property in Westwood Road came along. I was supposed to be one of the three people to move in but it was a bit of a dream for me. I never actually got down to see it. I don't think the idea was as real to me as it was to the other two involved and I was not very upset when the Housing Association lost that property a little later.

OXFORD STREET

A year passed and then a big house in Oxford Street came along. A lot of personal things had been happening to me during that year. I was growing up very quickly. I did not really know what I wanted to do with my life most of the time. I was able to explore a lot of ideas and possibilities through Project 81 and it gave me something to concentrate on. I was now certain that I could not see myself in any type of Residential Home in the future.

I intended being one of the three people to live in Oxford Street until I saw the place. I did not like the building, but the others were so enthusiastic about it I thought there was something wrong with me. Also as we discussed details I found that our ideas of care were totally

different. I felt that I needed to have someone around me all the time, whereas the others did not and I was scared. I did not want to be isolated. I could see that if the others achieved their work ambitions they would not be in the house all day, and I did not want to be at home on my own.

A LITTLE PLACE OF MY OWN

Around this time I went to see my sister. On the visit I was looked after by a Danish girl called Merete. We were talking about Project 81, and I had said I was very undecided. I said that what I would really like was a little place of my own with two people looking after me. Seeing at close hand the ordinary domestic life of my sister put this in my mind. I realised that I fitted happily into that sort of setting. Merete suggested I try and do just that.

When I came back to Le Court I asked my closest friends, Paul and Helle, if they thought I could do it. They were a married couple living in the community. They had met each other at the Home before moving out, 'one a Resident and the other a member of the Care Staff. I was very unsure of myself and I needed someone to help me make up my mind. They said, "If you want to do it, you can, and we will help you."

I talked to Ann Parkes and asked her what she would do if I dropped out of the big project in favour of something of my own. She replied she would help me get what I wanted.

IDEAS INTO REALITY

Next, I wrote to my home Social Services and asked them what they would do if I moved from Residential Care into a home of my own. They said I would become the responsibility of the local county and that they would not help me. At the prompting of my friends I wrote back and asked them why not. They sent a social worker to talk to me. She admitted later that she came thinking this was some hair-brained scheme, but left with the understanding that it was a well thought out and well planned idea.

My friends from Project 81, the Head of Home and the Head of Care at Le Court worked together in order to present a convincing case. Our proposal was based on the fact that living outside would possibly be cheaper and, if they didn't agree to pay for me to do so. I would remain in the Home as an expense to them anyway. Soon after this I received a

favourable response and I began house hunting and discussing the details of how to meet my care needs.

Much later in February 1982, a senior representative of the Authority came to another meeting to discuss the details. He confirmed support for my idea. The Authority agreed to top up the difference between what I would get from the DHSS and the full cost of meeting my needs.

The only real hiccup was that the local DHSS would not assess my Benefits until I had moved in and my Social Services were not prepared to finalise the amount of their commitment until they knew the DHSS and so we went around and around in circles, trying to get some idea, but never succeeded. This was a worry to me because I could not work out how much money I would have to live on.

HOUSE HUNTING

Through my experience in Project 81 I knew that I wanted a bungalow. If it was my home, then I needed to be able to see everything. I wanted to stay in Hampshire and I had to fit into the prices the Housing Association could afford. I wanted to be near to shops, that is, within the range of my electric chair. And, apart from these I had no other preferences.

I saw my new home in October 1981, it was about the seventh or eighth place I had been to look at. Ann came down and agreed the property was suitable. The Housing Association Submitted the project to the Housing Corporation before Christmas and the project was quickly accepted. Then there was a long wait.

£5,000 was needed for adaptations. This was much more than we expected and was largely due to the need to raise the path to the front door which involved re-locating two man-hole covers. Ann and the local Occupational Therapist had a meeting to talk about funding the work. I asked which would be quicker, the Local Authority or the Housing Corporation? They suggested the Housing Corporation.

DELAYS AND FRUSTRATION

Everything took an age. At first the cost was queried by the Housing Corporation. Eventually they agreed to go ahead but already 1982 was well advanced. Then the building specifications had to go out to tender. The tender had to be accepted by the Housing Corporation and then the builders had a summer holiday. The builders said the work would take

six weeks so I planned to move in after this, at the end of July. And when the time came around the work had not even started!

COMING, READY OR NOT

I sometimes doubted that I would ever move. At other times I just felt the waiting was going on and on far too long.

People at Le Court were interested in what I was doing and I told them what was going on. I felt that as they had endorsed Project 81 it was my duty to tell them. I don't know if the residents believed I would ever move. I never got any comments, except, 'How's it all going?' and, 'Isn't it taking a long time?'

I think they were trying to support me to stop me getting depressed about it. Going up and down the A3 about three times a week to see the bungalow did get a bit much.

In August, when the builders still had not started work, I decided to move in September, ready or not. I had already employed an Attendant, Toril, who had come over from Norway at the end of July to help me during and after my move. Toril had planned to work for a few weeks at Le Court and, in her spare time, begin to move things into the bungalow. However that didn't prove possible as we had to wait.

PLANNING MY NEW LIFE

During this period I finalised the details of how my care needs would be met. I felt that I needed someone to be with me all day and all night. I did not want to be left on my own. My idea was to have my Carers living-in. I did not like the idea of people popping in and out to see to me. I had some experience of this when I lived at home, having to wait hours for the District Nurses.

I prepared an around-the-clock chart detailing all my care requirements. I counted up the number of hours needed per day and multiplied it by seven. It came to something like 60 hours and I decided that I could share it between two people. I costed this on the basis of staff receiving standard wages and being told on their contract that they would work 30 hours, to cover 24 hours a day. So that they would know that they were really getting paid for the time they were actually doing something, and not when they were in the house.

A HOME AT LAST

When I finally moved at the end of September, this was an enormous step in my life. Further, it was a huge step for the staff and everybody else associated with me, because this had never been done before.

EARLY DIFFICULTIES

On top of this there were practical pressures that made those early days very difficult. The fact is, I did not go into a perfect situation. The building work was not complete. Indeed, the kitchen was not finished until January, and we had to live off a gas primus stove. The conditions made everybody uptight and it was very difficult to have a normal working atmosphere.

What annoyed me most was the red tape. The kitchen was not done because the Local Authority could not produce the money until I was a tenant, and I was not a tenant until the builders finished. And so it was not until January, four months after moving in, that I had a reasonable chance of settling down.

I could not get into a routine because there was nothing to get into a routine with. Besides the problem with the kitchen, there was no central heating, and my room and the bathroom were incomplete. For the first two weeks I was living in a double room with Toril.

It was all so dreadful, but. I don't really remember it now. More than anything else I think I was worried about what other people would say if I failed. A lot of people were waiting to see what happened to me. Everybody wanted me to succeed, and I was scared I would fail I think they thought they were supporting me, by saying, "You'll be OK," but really it just. increased my anxiety.

I hadn't anticipated so much pressure in my new life. I had not been prepared for the volume of decisions I had to make. Simple things like: sorting out looing routines; how to use the local laundrette; finding out where all the Allowances come from and how to get them; sorting out local trades people; sorting out dustbin day, milkmen, a doctor, a chemist; and so on. But above all it was the incomplete building work. I was trying to start a new life on a building site !

ADVICE AND SUPPORT

In these early days I got overwhelmed very easily. Sometimes I thought that within a few months I would be back in Le Court, because I did not think I could continue. If I had not had the Support of Project 81 members, the Head of Care at Le Court and other friends, I do not think I could have survived.

All sorts of things seemed to flood in including the fact that I was not getting on with one of my Attendants. She decided that she did not want to stay because she did not like the job. She felt that she did not have enough to do. I found it tiring to have somebody in the house who I knew was not really enjoying what she were doing. Sometimes we annoyed each other. It was the long dark evenings, the unfinished building work, the awful weather of Autumn and we could not get out. I was not prepared for these inter-personal difficulties. Precious moments of light relief came when a couple of friends would turn up out of the blue and say, "Come to the Indian Restaurant". That sort of thing was invaluable.

Paul and Helle supported me in another way. They acted almost as a Samaritan group for me. I knew I just had to ring them up, and say a certain sentence, and they would come down to see me straight away. I never actually had to use this code though once I got near to it, but it was nice to know that they were there.

Since those early days I have grown considerably in confidence, on top of which all the furnishings and fittings are complete. This makes a very big difference! I look back now and wonder how I managed. Really, I moved into a building site and tried to make a life whilst work was in progress!

THE NEIGHBOURHOOD

I like the area, it is friendly and peaceful. I think I could probably leave the front door open all night and nobody would walk in. It is only ten minutes to the shops in the wheelchair. It is good for me to get out and do the shopping, I enjoy that bit of fresh air every day. It is something I have got to do. That is when I meet people.

My neighbours are friendly but I don't really know anybody intimately. I know a lot of people to say "Hello" to, but that is about it. The guy across the road sort of keeps me up on what is going on, and I have got to know his family quite well. There is always somebody there. We have told them about my alarm system. They would do something if they heard it.

I don't feel that I have succeeded in mixing with the community as well as I would like to have done. I think that mixing is difficult because many houses are not accessible and so I cannot just 'drop-in'. Also, we haven't got things in common -like kids. I go to night schools and force myself to mix, but I only tend to socialise with my present or former care assistants, former Le Court friends, and people that I have met through HCIL.

DIFFICULTIES

I have had various small problems. Finance is always a worry - but that is true for everyone trying to live on Supplementary Benefit. At the moment I need a Clothing Allowance. I have not had new shoes for some years, and I can't afford to because my feet need soft. leather shoes. Now I have to go through all the rigmarole of proving that I need these shoes.

I have had difficulties with the Housing Association who own the bungalow. For a long time I was worried because nobody checked up that the house was alright. Very recently they arranged an external maintenance check and subsequently had some work done, much to my relief .

Another problem came to light when one of my care assistants was taken ill while I was still in bed. I realised that I had no way of contacting the outside world, so now I have a telephone by my bed.

IN CONCLUSION

I feel settled in my home. It seems as if I have been here a lot longer than a few years. I do not think that I could ever fit into an institutional regime again.

People say I have changed as a person. I don't know. I think I have become a bit more positive. A home of my own has given me confidence. I expect people to regard this as my house and not to abuse my privacy.

I share my home with my dog Holly. I couldn't think of living here without her. She relies on me. I rely on everybody else, but she has to rely on me for her food and comfort. She also helps with the care assistants, giving them something to do when they are not dealing with me. She helps break the ice when I am interviewing. When I am out walking,

people stop and talk to her. Instead of saying, "What a nice chair", they say, "What a nice dog". She barks at anything in sight, but doesn't bark at night! She would probably lick an intruder to death.

As for advising someone else wanting to do the same thing as myself, I don't know what to say. You cannot write a book to tell people exactly how to do things because things change all the time.

The idea of people coming and saying , "I want to move out, what shall I do?", worries me. I would not know how to tell them what to do, because their disabilities are completely different from mine, their attitudes are different, their ideas are different, their hopes are different.

All I can do is to share my experience with them and tell them how fulfilling I have found it all, and how I have grown as a person.

PRACTICAL DETAILS AND SOME OF THE LESSONS LEARNED

RELATIONS WITH SPONSORING AUTHORITY.

To finance my care needs, Le Court bill my Sponsoring Authority every month, as if I was still living there. Then Le Court pay the money into a "Care" account where it becomes my responsibility.

I have records of all care related expenditure, because I have to do 'Pay and Deduction Worksheets" every week for the girls. I also note any casual money that I payout. I feel that my Sponsoring Authority are happy to let me get on with it. I think their attitude is that if Le Court are happy then everything is ok I am quite satisfied with this arrangement.

I have to apply for an increase in funding every year to account for inflation, but I do not always do so. It depends on how much I have left in the "Care" account at the end of the financial yea. I try to keep a small float which is my emergency reserve, to cover extra costs incurred through personal or carer illness. If this reserve goes down too low I ask for an increase.

I have kept my social worker up to date with how things are going, and when I visit my parents she sometimes comes to talk to me. I have invited her down here but she has not been yet. I think my Sponsoring Authority have been very far sighted in their treatment of me. They have never interfered.

WORKING ARRANGEMENTS

The working arrangement have changed over time. Originally, at the suggestion of care staff at Le Court, I had two Danish girls who lived in. They worked alternately, two days on, then having two days off. We did that for five months.

Later on the pattern changed. I decided that as long as each girl worked seven days out of fourteen, including one Saturday and Sunday, they could choose their own times provided they let me know in advance. We sat down and planned ahead, so I knew who was doing what, and when. That worked for quite a while.

There was a period where instead of two overseas girls, I had a local girl to work for me. She liked to go home on her days off and I found that very helpful. Now I try to have only local girls. The pattern of work is three days one week, four days the next, and I prefer them to go home on their days off.

The only time I ever worry about depending on just two people is on the changeover day, hoping the other one will come back. They always do, because they are very reliable people. One day though, perhaps a girl is not going to come back.

Some people have said it is necessary to have a number of attendants to spread the load and vulnerability. I don't think I could cope with four or five attendants. I think for my own peace of mind I need to get to know my attendants quite well, and with four or five people I think that would be quite a job.

I have had someone sick and not able to look after me. Luckily Helle was here so she took over.

Paul and Helle have always said that if I do have an emergency I am to try them first, and they will come straight down and look after me. I have a contact in the local Care Attendant Scheme and in a real emergency situation I could use them. The Head of Care at Le Court once said that if I am stuck, I should ring her up and she would try and do something. But I would never get to that stage because I have tried to develop my own resources and I think I could possibly rustle up something myself.

The longer I live here the more people I get to know who can give me a hand. I now have local friends, and others living in Portsmouth, Oxford

and Bognor Regis, who I have kept in contact with when they moved on. And I have a friend living locally who has her own need for care and her own sources. She too would help me out in emergencies. And of course I could ask whoever was working with me at the time if they would mind working another couple of days, and pay them extra.

THE DAILY ROUTINE & HOUSE RULES

Each girl receives a letter in the form of a job description before she starts. After her month's trial period, if all goes well, she then signs a contract. This tells her that she is employed as care staff working 30 hours a week; the commencement and termination dates of employment; that she has the right to join a union; and, that the accommodation provided is for her while she is working for me.

I discuss the house rules before each girl starts working for me. The main rules are that she is not to play the ouija board, or smoke pot. She pays for her own telephone calls. I used to ask for £10 a week towards a communal purse for food but this proved expensive for all of us. Now I ask for £1 a week towards coffee, tea and biscuits, and each of us pays for our own food. Usually this means sharing the cost of the main meal. I keep a jar for the milk money.

The girls can have friends to visit as long as I know that they are coming, but I find that they like to keep their friends for their off-duty days, so I tend not to get many extra visitors belonging to them.

It is difficult to say exactly how the care hours work out on a daily basis. It is so informal, I don't think anybody really notices. The day always starts with getting me up and having breakfast. Then I say what we are going to do that day. It could be local shopping; or bung some washing in the machine; or I could ask the girl to go shopping in Waterlooville for me, which can take three hours.

Originally when the routine was two days on, two days off, the girl had a couple of hours to herself in the afternoon. But in the present arrangement I only call her if I want something.

The girl knows vaguely when I need things done, and for the rest of the time she keeps herself occupied. Basically the girls know that they work three and a half days being a companion as well as providing care.

LEARNING BY DOING

I made a lot of mistakes early on from which I have benefited. I have learnt that people like to know exactly what is expected of them. Now I feel more confident in that I can tell people what I want them to do and what they are not going to do. In the beginning the girls paid their share of the rent. I got it thrown in my face that it was as much their house as it was mine, so they could do what they wanted! That has changed now.

So far, I try to think of the girls as friends, and they have all treated me in the same way. We occasionally sit and have long talks about how we feel about the job. They tell me and I tell them. We have to get on, it is give and take all the way around. A common topic is confidences. If I talk to them about something, it should not go outside the house, and if they talk to me, then I don't repeat it. It is like being married.

The Head of Care at Le Court had warned me that things would not always be plain sailing, and that everybody's personality is different. However nobody could really tell me what would happen when I moved out, mainly because nobody had done it before!

There were difficulties in the early days but I never felt that the two girls were against me or taking advantage of me. When we had differences I said, "I'll have got to learn to live in this sort of situation as well as you, so bear with me!" And they did.

It is so much easier now, I find it hard to remember what those early days were like! Today I tell the girls that there is not a lot to do some days, especially if I am busy and I don't need any help. I have explained this to all the people that have come here as a result of early experience. One of my first girls was unhappy as she found she had too much time on her hands. Now the girls come on the understanding that they will have this time, and most of them have their own things to do.

HOLIDAYS

The girls have one week paid holiday for every three months they work. Usually they know in advance when their holidays will be. As they only work three days one week, or four days the next, it only means three or four days to cover when they are away. I use local people who used to work for me, or friends who happen to be around at the time.

I cannot go on holiday myself unless I take my care with me, so I take one carer and she gets paid the normal rate, as if she is only working half the week. She comes on the understanding that she is working for

the whole week and I pay her travelling expenses. She only provides her spending money, I pay for everything else from the care money.

It is a difficult to go on holiday for more than seven or eight days, unless I go with a friend, who can look after me as well.

As an employer I am responsible for PAVE and National Insurance. At first this seemed very complicated, but now that I know what I am doing it is pretty easy. When I first moved the accountant at Le Court did most of the ground work. He put me in touch with the local tax office and the big one at Chichester. Without his help I could not have coped. The alternative was a book of rules and regulations about half an inch thick! He did the work for me in pencil for a few weeks so that I could copy it. From then on it was up to me, but even now if I have any problems I can go back and talk to him.

I have a casual rate which is £11 a day, morning to morning. If anybody is only doing two days work in a week you do not need to declare it as it is below the taxable minimum.

INSURANCE

The girls are insured on my house insurance. They are insured as servants, and for damage to themselves. I am not insured if they damage me. I am not happy about this but the premiums for such a policy are more that I can afford.

RECRUITING STAFF.

I have tried various methods of recruiting staff. Originally I started with somebody I already knew who had worked at Le Court. She was interested in what I was trying to do and promised to come back when I moved. She kept to the promise. The other girl had written for a job at Le Court and was passed over to me as there were no vacancies. After that a second girl came here after working at Le Court, and then a local girl worked for me. She was looking for a job and was a friend of a friend. Since then I have tried other ways of finding suitable people.

NEWSPAPERS

Early on I tried advertising in The Lady but without success. Adverts are so expensive and you can't put much in. In The Lady I put, "Somebody to live in to assist with daily living requirements".

That did not produce much at all! Later I went back to using the word, "Care Assistant", because I think it put people off if they did not realise they would have to do the nitty gritty part of care.

I have only had one experience of using a local paper. It cost me £11 for one edition. I had a PO Box because I thought that was safer. I did it because a few days before that I had seen an advertisement from someone else looking for a' carer, so I thought I would try it. I had been warned that I could get over 200 replies, but I did not get one!

The advert just said, "Young carer-companion, required to work with young physically disabled female, to work on rota with second care attendant. To start September or December. Salary Whitley scale. "

I rang the paper when nothing came through. I thought maybe they had forgotten. They said that four replies had been sent down to me on the 27th, which was the day before the advertisement appeared. I didn't bother with them after that.

Community Service Volunteer (CSV)

At one time I thought of branching out and using a Community Service Volunteer (CSV), and I investigated this. I did not want to replace both my staff, but thought of having one CSV , working alongside someone more permanent. This did not materialise, primarily because the CSV organisation require a supervisor to ensure the well being of their volunteers, and the only acceptable local agency, the Social Services, would not co-operate. Further, I came to realise that using a CSV would cost me more than my other carers.

JOB CENTRES

This has been my most successful method of recruiting staff. There are six local centres. When I first advertised the text was: "living-in care assistant, 30 hours, basic pay, must drive, interviews."

Now I specify: "18-25 year old female care assistant to live-in while working 3-4 days a week Driver preferred but not essential."

This last time I was advertising for 6 weeks. I got three replies, 2 people did not turn up for the interview. The third person turned up - I offered her the job a week later and she did not want it. I had decided anyway that she probably did not want it, but she was the only one. When I rang up the Job Centres I found that they had been turning people away because they could not drive I have found that you have to chase up the Centres if things go quiet.

The Centres used to put my job under 'Nursing', but I asked them to put it under 'Miscellaneous'. I found that brought more enquiries.

QUALITIES OF A CARER

At first I thought that I would only employ people over 20. I have got two 19 year olds working-here now, and I get on so much better. I find the over 20s have already had a life, so they have more confidence, probably more than I have.

I usually look for local girls now as I have found this easier. I might have somebody from far away again one day, but I think I would have to find a room for her nearby, because I don't think she could live-in all the time.

So far all the girls have been single, though once I did have an enquiry from a married lady from the Naval base nearby. I presume her husband was away for a year and that her accommodation was provided so she did not have to worry about paying rent while she was not there.

IDEAL LENGTH OF SERVICE

I think that a girl should stay at least a year, and not more than a year and a half. The first six months seem to go by very fast. Six months is too short a stay, especially if you find that you are getting on very well. But after a year it starts to drag a little bit for both people. I find it much better if I have somebody who has a set date when they want to leave, like going on to training or another job. I tell people when they come for interview that they probably will not want to stay with me any longer than a year, and that they should think about that before they take the job.

As a deliberate choice I prefer not to have someone coming permanently. I would tend to rely on them, and they would tend to rely on me. There is a wage review every year but there is no career structure in

this job. They could not go on from me to something higher up the scale because there isn't anything.

THE INTERVIEW

In a way, using the Job Centre is a screening process. Only people who want to do care work ask for the interview. The person, if interested, has to go in and say, "I would like to try that job ". The Centre then asks them a few questions before they ring me.

Prior to inviting someone for interview I establish some details:

I make sure they are between 18 and 25 years old.

I make it very clear that I want them to go home on their off duty days. I don't want anybody who wants to live here.

I check on their previous experience. I have found that people who have worked in Old Peoples' homes have very different ideas on "looking after" me. So far I have only had two successes with girls who have done this kind of work. The problem is that they tend to try and take over, so I have to be very careful.

I check out their home address. Sometimes the area they come from is a problem. Round here there are some very bad estates and unfortunately you know that if somebody says they come from such a place you have to be careful. It is a shame but I am very vulnerable.

After that I ask them to come and visit me. I watch a prospective care attendant coming up the path when she arrives for interview. I like to see her size. If she is very small and slight, unless she can prove otherwise, then she is probably going to have difficulty rolling me about. I like to see confidence in the way she walks as well, because if she lacks even then maybe she is not going to be able to stand the pace. (It can be quite tough) I take in a lot before I start interviewing the girl.

I like to do interviews on my own. I always start by offering the girl a cup of tea or coffee. Then we pass the time of day. After that I say, "Right, I am going to tell you the conditions of the job and the job description and a bit about myself. Then you can tell me a bit about yourself and how you feel about the job".

While I am talking I watch how she reacts and what she picks up on. You need to have someone who is fairly open and sociable. I give the girl a brief history about why I am here. Some of them pick up on the Independent Living bit and say that they have heard about it, or that they know Cheshire Homes, or something like that.

It helps if they have a 'phone at home, and I like to know that they are living happily with their parents. I had the experience of one girl who had problems with her family and tried to leave home and live here. I did not realise what was happening until she would not go home. She kept making excuses. So now I usually ask the girls about their parents and how they get on with them.

Most people who come for interview expect me to be a child living with my parents, or that I have a husband, or that I am an old person, even though I put "young disabled lady". They are quite surprised when they find I am young and single.

I tell the girls that I have to ask them all sorts of weird questions like: If they smoke; if they are vegetarian; what are their religious views; political views; and so on. This is because they have got to live with me. Most people are scared. I am scared doing interviews!

After the interview I say, "Is there anything you want to ask my care assistant before you go?" and they usually say, "No". Sometimes they do and sit and have a chat with her.

I don't ask the girl to make a decision about taking the job then and there. Indeed I don't want to make a decision myself, especially if I have got a list of people to interview. I usually set a date by which I am going to stop interviewing and then set another date by which I am going to let everybody know.

I rely a lot on my own instinct in making up my mind. Although I ask about their previous jobs, I don't ask to see written references because it is up to me to find out within the month's trial. They all come on a month's trial. If I say, "If I want references can I get them?" and they say, "Yes" , then that is usually enough for me.

Once I have seen everyone and made up my mind I ring up the girl that I want to employ and offer her the job. If she accepts it I will then write and give her written confirmation along with the conditions of employment and house rules.

I also write to the people I don't wish to employ and say, thank you for coming for an interview at my house for a job I regret to inform you that the application has not been successful "

STAFF AGENCY

I have thought about a Staff Agency as a resource to turn to. It might be helpful to have an organisation that identified possible attendants and held them on a list, but I would still want to interview them as if they were coming in off the street. Such an agency or centre could be valuable for emergency cover, something like the Spinal Injuries Association care attendants scheme. This could be another source of potential care that could identify somebody living locally who might be suitable to come in to take over during a bad patch.

I know that some CILs in America have such a list with names and addresses of people available for an interview for care work. That would be quite good as long as I did not feel that I had to have a person simply because they were on the register.

ALTERNATIVE STAND-BY CARE ARRANGEMENTS

I have a helpful arrangement with the local Care Attendant Scheme Organiser whereby she is willing to try and help me out if I am in need of temporary care. It works out that I contact her about once a year. I pay the attendants directly when they do the work. I regard this as for emergency use only. The scheme will provide me with somebody to put me to bed, get me up and take me to the toilet in the afternoon, but they cannot provide someone to sleep overnight. On these occasions I try and find a friend to stay here at night.

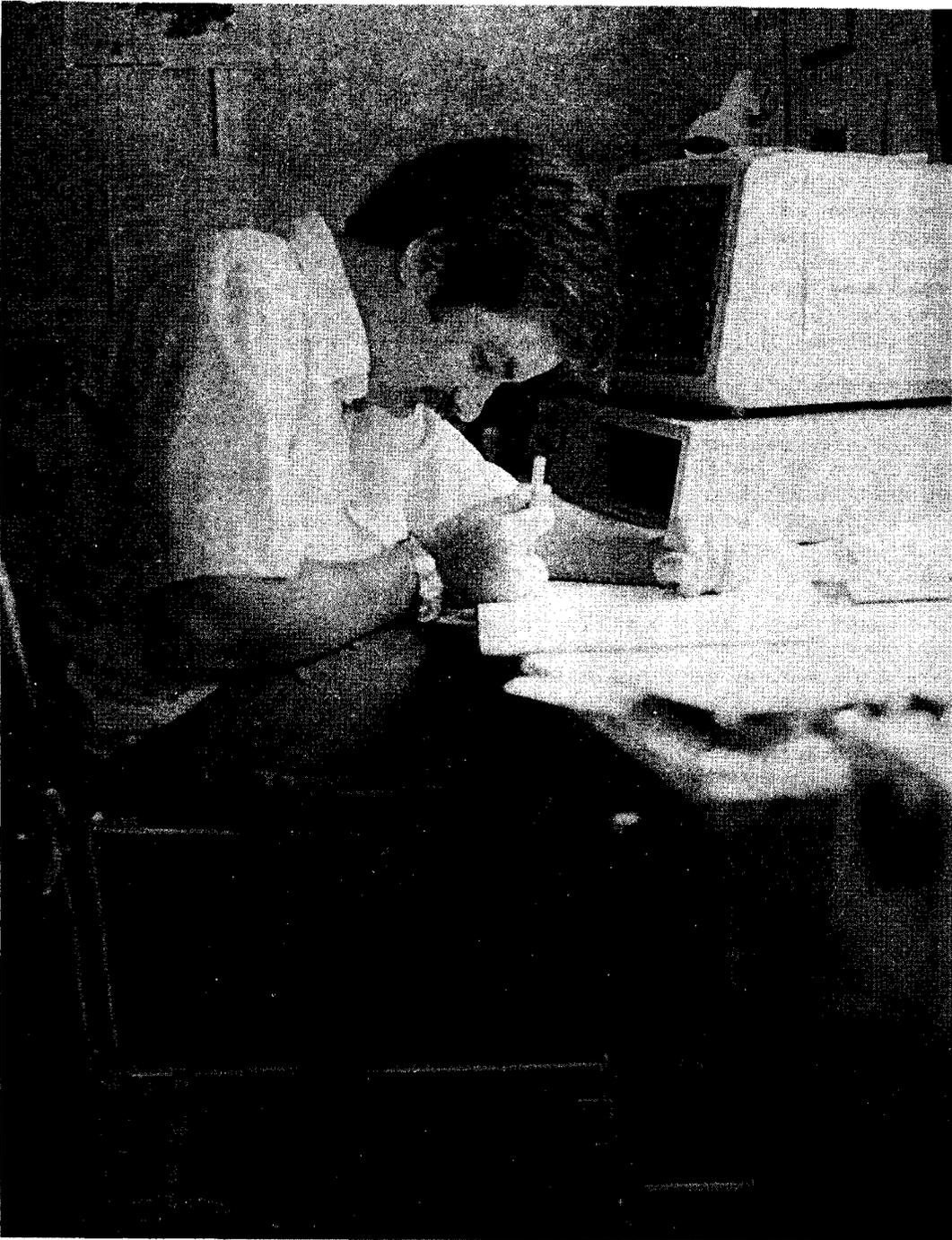
Alternatively I look to friends and my former care assistants to help out on a casual basis. It needs a lot of ringing around but I can usually find someone.

DRIVING

I have a van and planned my life on having girls who could drive, but that is not always possible. It is a little annoying occasionally. It is difficult to ask friends to drive me somewhere and then expect them to sit around for a couple of hours while I am in a meeting or something. Even so if anything very important comes up then I can usually make it somehow or other.

I have a local girl at present who is at college and who can drive in the evenings, so if I want to go and see one of my friends she can drop me off and then pick me up later. She has just passed her test and is a friend of one of my care assistants. She is a very good driver, and because she is young and strong she can handle me and the chair. Being a student any money that I can give her is useful. My Mobility Allowance helps with that. Interestingly, this same girl is probably coming here to work as a care assistant when she leaves college.

I have tried other sources of voluntary drivers, advertising and things like that, but not very successfully. It is better by word of mouth.



PHILIP

PHILIP

EARLY DAYS

I had my accident in September 1977, soon after my twentieth birthday. After a day in my local hospital, I was transferred to the National Spinal Unit at Stoke Mandeville where I went through the usual course of treatment. When the time came to leave, living with my parents was the only option considered. No alternatives were offered, and at the time, I wanted to go to , my parents' house because that was my home.

I remember an Occupational Therapist advising me that I had the potential to live alone. It was a vague suggestion, made in terms of my being physically able to "learn" to do everything for myself. I realised it was more an occupational therapy target than a reality. I had no wish to live alone. I realised that my care needs were high, and I could see no advantage in doing so.

I left Stoke Mandeville in August of the next year and, after a short stay at a Rehabilitation and Assessment Centre, I was home by September. I was very fortunate because my parents were both determined and able to do a great deal to meet my needs. They had speedily adapted the "Granny-annexe" before I came home, and later, through grants, willingly carried out other adaptations to the house.

We employed someone to get me up six mornings a week and the district nurse got me up the other morning. My parents put me to bed and did everything else. My memory of this time was that of always being physically washed out. I was so knackered that I did not really understand what was going on much of the time.

LE COURT

" Moving to Le Court was a conscious push. It gradually became clear to me that living at home could not be a permanent solution. My father likes getting his own way and so do I. Sometimes our ways are not the same.

Living with my mother and father as parents and carers was II totally unnatural for someone of my age. I felt it was detrimental to the normal process of growing up. Our relationship was dominated by the burden of my physical care and our being closeted under the same roof.

I first visited Le Court in February 1979, for a two week holiday. I hated it but realised it could be a suitable place for me. I returned there "on assessment" in June, with a view to becoming a permanent resident.

I did not consider anything apart from a residential home at this time. Le Court fulfilled all the criteria that my parents felt were necessary, and as it was the only suitable place around, it became a sort of Hobson's Choice. Also, I was still tired all the time, and it is hard to say whether I could have coped with anything else. I did not think about whether I would spend the rest of my life at Le Court. I did not think very far ahead at that time.

PROJECT 81

I found Le Court a very weird place and I felt very insecure. Gradually I started to get to know a few people, and I began to relax. My strength and stamina improved, and I started staying LIP longer and being more active.

I had arrived at around about the time a group of residents began talking about ways of moving out of the Home. They called themselves "Project 81" because they hoped to achieve their objectives by 1981, the Year of Disabled People. One of the group approached me and said, "Come and join us, we are trying to get a shared house in Petersfield". I had just spent months trying to get into Le Court, but I said, "Yes". I don't know why!

QUADRANGLE

Although I had not really thought about movingly and felt that Le Court was my home for the future, I did not dismiss the idea. It sounded quite attractive, even though it had not been described to me very accurately. I thought about it and developed an idea of my own which I called "Quadrangle". Because I had not really had any privacy in hospital, in my parents' home, and now in a Residential Homey I very much wanted something that was Philip Scott's place. But I envisaged problems with the social side of a lone house. I thought of a Quadrangle four houses built around a courtyard. However, this was never to progress beyond the "idea" stage.

WESTWOOD ROAD

Meanwhile the Project 81 group, in conjunction with the General Manager of the Cheshire Foundation Housing Association, were looking for a large house which the Housing Association could purchase and adapt for three of us to share.

In the Summer of 1980, a property came up in Westwood Road, Southampton. It seemed very feasible but it scared me, because I suddenly realised that some day I was going to have to stop talking about moving-out and do it. I remember thinking "Am I actually going to move out of cosy Le Court?"

Even at this stage I was privately inclined towards a more individual home, but I thought this might be a stepping stone. It was the only option I could see.

OXFORD STREET

Then in December we lost the Westwood Road property. In some ways this was a relief to me, although I was sad. Even so I was keen to keep things going. A number of possibilities came and went until, in the Summer of the next year, the Oxford Street project was proposed. This was another group home scheme in a large house in Southampton. Acquisition was unbelievably slow. We had the ideas and the enthusiasm but the process of gaining ownership dragged on, eventually taking over two years. There was never any doubt about the outcome and this certainty of a property, however delayed, prompted us all to think very carefully about our individual futures.

I was committed to the Oxford Street project, seeing the possibility of employment nearby. When the others dropped out I even thought of having a self-contained flat there. I desperately wanted to do something, but when we lost part of the proposed accommodation, my enthusiasm was severely dampened. Soon after this came an unexpected opportunity.

A TRIP TO CALIFORNIA

Early in 1982 I was able to visit the Centre for Independent Living in Berkeley, California. I met many disabled people living nearby and soon realised that you do not need to have lots of people around you all day and in the way that I had previously thought. What I saw convinced me that I could make it on my own, and that I would prefer to have the greater choice this gave. It was a big turning point. I was sure I had to do

my own thing. The fact that Liz had already made a similar decision did not influence me too much, only confirming my thinking.

I returned from America in April and wrote to my Health Authority proposing that they consider funding the cost of my care outside Le Court. I explained that I wanted to live in my own home, and asked them to provide the funding so that I could employ my own care staff. Their positive reply led me to believe that I would get what I proposed. I was unbelievably excited!

HOUSE HUNTING

On the basis of the Authority's response I talked with my parents and started looking for a place to live. My parents realised I was serious and were determined to help me. A "package" to buy a property was made possible. They started looking around for something they thought suitable and found a group of sheltered bungalows for "retired gentlefolk". I looked at it to keep them happy, but it was not at all what I wanted. When I explained how I felt about this it led to a "discussion" and greater understanding between us!

I have always lived on a farm, but! had been willing to get used to a town since Westwood Road. My criteria for a suitable property were that it should be: in an area that could provide a reasonable source of helpers somewhere where I felt I could "fit in"; and that it had to be in Hampshire.

I wanted to be in a friendly community, but also I wanted to be able to close my front door on it. I think I wanted to be near Le Court. Being near friends was important.

I started looking for, a property about a week after returning from California, and found my house four months later. In between I had looked at the details of 80 properties, viewed 42, and actually been inside 35! I used to get the brochures giving details, add up all the floor measurements and work out the floor area. This was a major determining factor.

I had thought of building a house at one time but that would have taken about 2 years. However this made me work out what I really wanted and so I had a good idea what I was looking for when I studied the properties.

EARLY WORK: ON MY CARE PROPOSAL

While the house hunting was going on I proceeded with the negotiations to meet my care needs. My aim was to have the house and the care arrangements ready at the same time.

Following the good response to my initial approach to the authority I submitted a more detailed Care Proposal in May. In this Proposal I listed what I considered to be my needs and showed how these could be met. I itemised the tasks, assessed the necessary hours to fulfil them, and the funds appropriate for the purchase of care for those hours. I tried to present a logical and persuasive argument as to why the Authority should support my move.

At the time I was more concerned with achieving the move than with the detailed working out of the care support, even so, my thinking when making the application has proved to be an accurate assessment of how things have worked out in practice. That is, having one live-in aid, supplemented by other people coming in as and when they are needed. I decided on this after seeing how things were done in Berkeley. It seemed to be the best way of meeting my requirements.

When detailing my needs in my Care Proposal I tried to err on the generous side, for fear of jeopardising my chances of survival through under-provision. As it has worked out, I require fewer hours than envisaged, but the hours I do have are more expensive. That is, experience has shown that there are extra costs involved in employing people besides their hourly rate of pay. These include items such as advertising, sorting applicants telephoning, insurance, staff sickness, training new staff, and so on. These should have been built into my original proposal but we were not to know that at the time.

I FIND AND WORK ON MY HOME

I was told about the house that was to become my home one morning in late August. I saw it that afternoon and I liked it straight away. The wheels were in motion to buy it by the evening and the house was mine by the end of September. I obtained plans of the house and worked out all the adaptations I thought were necessary. I prepared files of these to give to the various authorities as it was necessary to apply for grants to carry out the adaptations.

I proceeded with negotiations regarding the adaptations before I took possession of the house. I arranged a site meeting with: the Local Authority Housing Department Grants officer; the local Occupational Therapist from the Social Services; a representative from a local kitchen designer; a local builder of my choice; a representative from the company supplying hoists for the Health Authority; and a friend, who had recent experience of a similar undertaking.

I deluged the appropriate people with hundreds of bits of paper from the prepared files. Their response was fantastic, particularly the Occupational Therapist and the Housing Officer. I received a Home Improvement Grant and topping up from the Social Services. The house became mine on a Monday. On Tuesday I got the "go ahead" , the builder started work immediately, and within three weeks the place was ready for me to move in.

I enjoyed this period immensely. Each day I visited the building work, noting little problems and working out solutions. I am pleased with the result because it has turned out much as I planned. I intentionally worked for the place to be standard and not a "disabled" bungalow. A place that could one day' easily revert to the open market .

GETTING TO KNOW MY HOME

Visiting while the building work was being done proved valuable not only because I could make sure my wishes were carried out, or to answer the many little questions that arose, but, more importantly for me, because I gained a mind's eye picture of everything in the house, where it was and how it worked. I wanted to know about the systems and how to find them, and to be able to explain this to someone else. I cannot necessarily get to or see everything, so having a fuse changed, for example, is quite different from doing it yourself, and much more difficult. Being able to describe what to do while lying in bed in the dark is a great help.

After submitting the detailed Care Proposal in May, I had read thinking the wheels of bureaucracy had been sufficiently in motion.

By mid August, concerned that I had heard nothing further, I phoned the Authority. I was given to understand that everything was alright. Apparently it was intended to take my application to the Joint Finance Executive at their next meeting. However, the date of the meeting passed and nothing happened. I now began to contact the Authority

regularly. They were unwilling to write letters, but I received verbal assurances that matters were in hand and care funding was imminent.

As more time passed and no agreement appeared I enquired in greater detail about the state of discussions concerning my Care Proposal. I learned that, although litany branches of the various statutory services were aware of my intentions, the details had yet to be discussed at the decision making level. Somewhere along the line things were being held up.

MY FIRST LIVE-IN CARER

A friend, Inge, had agreed to help me move and be my first carer. I met her when she was working at Le Court. She had left soon after I returned from the USA in February. Before going home to Denmark she had told me that she would return when the funding came through from my Care Proposal. We thought this would be around August. The plan was that she would come and help me set up home and stay on for three or four months afterwards.

As it turned out, Inge did not come to England until October, and then only because she either came then, or not at all. She had to decide what she was doing in that academic year. This situation had been brought about by the indecision over my Care Proposal. I kept being told that a positive response would come from "the next meeting".

When the house adaptations were finished Inge came at the expense of my parents. She moved into an empty bungalow while I was still at Le Court. This was not what she had planned to do and it was quite difficult for her. Even after she arrived there were a series of further postponements. Each month I was given to understand a definite and favourable decision would be made, and each month brought disappointment. As the months slipped by Inge understandably found the uncertainty very trying.

COMPLICATIONS AND FURTHER INDECISION

At one stage I learned that the Community Physician had decided to base the costing of my proposal on formal nursing criteria, thus doubling the funding necessary. Fearing this would jeopardise my application, and believing this Interpretation to be contrary to the spirit of my intentions I sought a meeting with the officer concerned. Along with members of Project 81 and my Occupational Therapist, I visited him in the hope of

dissuading him from this course of action." Regrettably our arguments were overruled on the basis that, "We didn't know what we were talking about"

We were told that the medical profession knew best as they had the experience of caring for severely disabled people! I was informed that I would always require constant, that is 24 hour, attention from fully qualified medical staff! My severely disabled friend and his long time carer were particularly astonished.

After this experience I chose to take my case informally to other people who I knew would be involved in the final decision. " I wanted to make it quite clear to them that I dissociated myself from the sums of money being discussed. I met some members of the Social Services in November and, after a long discussion at which my plight appeared fully understood, I left, feeling that at last something would happen. But it did not.

WAITING IN THE DARK

I was growing increasingly concerned. There appeared to be some discussion going on, yet nothing was communicated to me. I had little or no idea what was happening. I did all I could to bring my plight to people's attention but felt much in the dark about what was actually happening - even to the extent of wondering if anything was happening at all!

During these months I became aware that my case was the subject of discussion for two entirely different District Health Authorities, and two very separate departments of the Social Services - the local office and the head office it was like wrestling with an octopus - no single person or office appeared to be responsible for promoting my cause. Nobody seemed to know what the other limbs of the services were doing; nobody ever advised me or kept me informed of what was happening.

I began to feel that mine was an interesting academic case" to be savoured, and that there was not actually someone's life involved. I appeared to be the only person interested enough to chase the matter up, and in truth, much of the time I felt that I was going around in circles.

I was never invited to discuss or present my proposal. I was not consulted. The only way I could keep in touch was by persistent enquiry

through various channels, including on two occasions, general letters of appeal, written out of desperation.

At one point I was "unofficially" told by a senior officer that there was no chance of my application ever receiving a favourable response. This was a shattering revelation.

HOPE, THEN JOY

Then, late in November, the Health Minister spoke in Parliament introducing a Green Paper which discussed ways of promoting "Care in the Community". This, more than anything, seemed to stimulate action, more for the spirit of its message rather than the details.

Even so my proposal was not brought to the decision making forum until January. Meanwhile Inge had gone home for Christmas and returned still e of her future employment. At the January meeting of the Joint Funding Committee an agreement in principle⁷ based on my Care Proposal, was arrived at, subject only to a discussion between the Authorities and Le Court over the means of payment. This agreement was to run for two years.

My relief on learning this was indescribable.

Even then, instead of being treated by the Authorities as if I were the most important thing in the debate the only official notification I received was a photocopy of a letter to someone else.

THINKING ABOUT THIS PERIOD OF WAITING

In a sense I did not know how bad the waiting had been until it was all over. My feelings were so often clouded by other issues, such as things that cropped up on a day to day basis, that I was spared the full agony of uncertainty. Perhaps I busied myself to keep from thinking? Whatever, it is only now that I can look, at it all and know that I could never wish that four months of anxiety on anyone.

It is difficult to recall the bleakest moments of those months - fortunately the pain is readily erased. I always believed I would succeed and remained buoyed up by the prospect of the ultimate goal. Throughout, I was determined to do all I could to make it happen and in the end, if it did not, I knew it would not be for lack of trying on my part.

THE ROLE OF FRIENDS AND FAMILY THROUGH THE DIFFICULTIES

I enjoyed considerable support and encouragement throughout these difficult times, particularly from my parents and friends in Project 81. I have to say that I am deeply indebted to these people and wonder how I would have coped without them. Their moral support and practical aid helped me through the bad times.

THE ROLE OF AN ADVOCACY AGENCY

This help does not diminish the potential role of a formal advocacy agency. On the contrary, I suggest such a body would be essential to the survival and success of a similar venture. The Project 81 group provided considerable advice and personal support, but did not have the recognition of the Authorities to enable it to act as a significant advocate on, my behalf.

I felt I had to fight for myself. I think that a recognised consumer advocacy agency could have entered into a different kind of relationship with the Authorities -speaking up on my behalf and working with me to represent my interests. I found it very hard to argue on my own behalf.

I felt selfish, ungrateful, embarrassed - often with the sense that I was being done a favour. In addition I was reluctant to do or say anything that might prejudice my treatment by the Authorities. Unreasonably perhaps, but I was inhibited by the thought of a bureaucratic backlash or victimisation were I to rock the boat ! That is not to say that any of these repercussions ever materialised or were threatened - but it is the possibility, the thought, that inhibits.

The backing of an established consumer agency would have been a great comfort and support in all this.

OTHER PEOPLE AFFECTED BY THE INDECISION

During the four month period of waiting I had organised three "gearing up" staff meetings, just before each promised decision date". This was necessary because finding the right people to supplement the role of my live-in carer took time and I could not move until they were found and briefed.

Each time I called my proposed carers together and discussed my routine and where they would fit in, only to have to disappoint them all a

few days later. Each time there were five or six local people involved, each recruited after considerable effort, only to be put off.

I think my credibility must have begun to wear thin - remembering that none of these people had come across what I was trying to do before, and some were not entirely convinced of their ability to satisfy the confidence I had placed in them. I could have done without the postponements just for their sakes alone! I must say these folk exhibited extreme patience in what for everyone were very strange circumstances.

MOVING - PRACTICAL STEPS

As soon as I learned of the provisional agreement on my Care Proposal I notified Le Court and Inge that I would move on February 1st. Then I spent some time discussing the practicalities of the agreement with the Head of Home. This was necessary as it was proposed that the Home should act as an intermediary for the transfer of my care funds. We soon arrived at a procedure agreeable to all three parties involved.

The final step of the move took very little time or effort as I had been gradually transferring the focus of my life to my own home ever since October. In a sense I had long since committed myself to the move.

FRIENDS AND NEIGHBOURS

Some friends lived in the immediate area that I was moving to and they were able to introduce me to the neighbourhood. This was an important consideration in determining my choice of home. It is hard to recount the many minor, and sometimes major details supplied by these friends - apart from the reassurance of having people to call on if in difficulty.

I needed all the help I could get. I was taking over a new house, setting up home for the first time, and moving into a new area. Hurdles enough for an able-bodied person, before one considers the responsibilities of arranging and overseeing the adaptations of the property, and then the whole business of organising my care. I had enough to deal with quite apart from the constant uncertainty during the months from October to February.

MY ROUTINE TODAY AND OTHER WORKING NOTES

I have one live-in carer who works for five days and then has two days off. On her five working days she gets me up and then helps me run the

household -washing, cleaning, cooking, shopping, and so on. As long as I get the help I need and the usual housemaking chores are done the carer's time is flexible. I plan on her being in the house at night, in case of an emergency, but otherwise she is free from 6.00 p.m. onwards until next morning. If she is to be away at night then I need some notice so I can arrange for someone else to sleep in.

All the other hours and chores are covered by people coming in on an hourly basis, as and when they are needed. That is seven evenings and two mornings are shared between five other people.

I have consciously tried to spread the load and involve local people. However it is a situation I arrived at with much hesitation and apprehension. I wanted to know the people who are for e and I did not want my house to become like Waterloo station with an endless stream of unknowns coming and going. In fact, that does not happen, and I find I quickly get to know them well. If they come once a week there is always something to talk about, and that makes a big difference. After a while you do not have staff you have friends who work for you.

EMERGENCY CARE

I have no arrangements with the local care attendant scheme or Le Court in terms of care emergencies. This is a matter I expect to deal with myself and I said as much in my original Care Proposal. I have a mental list of friends I can ask to help in an emergency.

I think the SIA Emergency Care Attendant Agency is an excellent idea and have even thought about it for myself. However I feel it is my duty to be properly organised with my local emergency procedure and not to rely on a national organisation.

STAFF HOLIDAYS

The live-in girl is entitled to one week's holiday every three months. I have several friends who are willing to come and live-in while she is away and I pay them on a casual basis. They receive the same as I would pay the full time person. The II casual workers do not get paid holidays.

STAFF SICKNESS

I have to bear in mind that the live-in girl may become ill. It is important to be aware of her needs, and if she does fall ill, I have to call on my

emergency resources. As with holidays, it costs double when the main carer is ill, as she still gets paid. So far I have been very fortunate in respect of staff illness.

MY HOLIDAYS

There are two types of holiday: one when I am going away to do something in particular and plan this well in advance, such as when a friend and I went to do some work in the States. That was timed to coincide with the live-in carer's three monthly holiday, so while she was away we were all away. In that situation a friend agreed to look after me for nothing and I paid his travel costs.

The second sort of holiday is when I feel I need to get away for a break, and I pay for my aid to come with me. I just take one aid and I have to be careful not to work her too hard.

Of course, I cannot reasonably ask people to pay their own travelling expenses, so the overall cost rather limits what I can do. The great problem when I go away is that I have to manage without the usual aids and adaptations that I have at home. I try to go to hotels where I can ask a porter to help lift me out of bed, but not all hotels will let you do that! I would not go away for any great length of time in these circumstances.

FINDING STAFF

Advertising in Newspapers: I have had only limited experience of using newspapers, mainly because I feel you cannot get across the subtlety of what you want. I also hesitate to put my name and address of phone number in a public publication and have not tried listing a Box Number.

Job Centres: Job Centres are very good. Until I actually used them, I thought they would be much less fruitful than they are. You can get national coverage free, compared with having to pay for a single advertisement in a newspaper. I have found that you have to be careful to give facts and figures in the advertisement, and stress the professional nature of the job.

My advertisement appears under Miscellaneous rather than Nursing. The Job Centre staff sift and pass on much more acceptable applicants than you would get otherwise, and because some screening has already been done, you only meet people who are looking for that sort of job.

I would recommend the use of Job Centres.

Other sources of staff: I have found word-of-mouth the most successful for casual workers. I have met staff through social contacts, friends, friends of friends, former staff, and church.

Also, from time to time, I ask at the local post office. I have got to know the postmistress through going in for my Benefits, and she has been most helpful.

CARE ATTENDANT AGENCY

The idea of a local agency that might identify and hold a list of potential carers would be exceptionally helpful, because when I advertise for care staff I am always faced with the problem of people not understanding what is needed. Anything to reduce the hassle of finding people would always be helpful, but, of course, if there was a care agency, the user would still have to be in control of the hiring and firing.

WHEN CHOOSING STAFF

I know what I want when choosing carers, but it is hard to describe. For example, Mary, she walked into the house and immediately I liked her. Although we still went through the interview, I knew I liked her from the beginning.

I have been wrong. On one occasion I was unsure of someone and subsequently found them to be much nicer than I had first thought. There was someone else I made a mistake over, but she resigned after the first day, which was fortunate.

The sort of person I look for is not the most efficient, the smartest, the most intelligent, but a person who can become a friend. That is the most important factor.

Obviously I go to greater lengths when I am choosing live-in staff than casual staff. Even so the selection criteria are much the same.

If I have a list of questions that I ask. I sometimes ask for references, it depends on the person. I shy away from those with previous experience of care work, as I feel someone totally new to the job is usually far better. Certainly previous nursing experience can be a disadvantage.

Age is not important as long as the person is physically able to handle the job, and not too old and set in their ways or too young emotionally.

I would never want my personal needs to conflict with those of a family. For instance, if a person has young children, obviously it is important that the children come first. So I try to avoid that possibility, but it is not easy.

A phone is especially important for casual staff. If they are very local a car does not matter so much, but it is preferable. I would hate anyone who had come to work for me at night to be attacked.

In the end my choice is based on my gut reaction. I try and frighten them when I interview them. I try and paint the worst picture, all the personal care details, and see if they can handle that. You have to be sensitive to their reactions as you speak about "problems" and judge accordingly.

When Mary came round, she was friendly. We chatted and I knew that she was someone that I would get on with. Besides, she came from a known background as she had been introduced by a friend.

A TRIAL PERIOD

I do not have an official trial period for new staff because I feel that would add unnecessary strain to the situation. I think it is a good idea to agree to discuss how we are getting on after a month, but the most important thing is to really emphasise the fact that we will talk about things as they crop up. If my carer feels manky about something, then I encourage her to say so.

I have an agreement to terminate employment within two weeks, and she has the opportunity to hand in notice of two months. It is different for casual staff. They can terminate as soon as they like and vice versa.

CONTRACTS OF EMPLOYMENT

For part time staff there is no contract, but for the live-in staff it is important to have one. Sample contracts are available from many high street shops, and can then be tailored, to one's requirements. The contract gives a job description, a job name, amount of notice required on both sides, and so on.

The job description is not very detailed, it just gives a general guide, such as, "working daytime, not evening...". It is quite loose and needs to reflect the nature of the job.

A bricklayer starts work at 8.00am and finishes at 5.00pm and lays bricks all day, but in this sort of work there is no such thing as a standard day.

The need for flexibility means it is impossible to have a time-table. What is important in these circumstances is that I must be careful to be fair to the live-in aid. I must listen to what she says, and allow her room to live her own life. It is in my interest. I must remember that despite the contract she can always pack up and walk out.

HOUSE RULES

At first I had no house rules at all but later I found it necessary to develop some. Different people require different house rules, depending on how mature and responsible a person is. My house rules are a verbal agreement. They cover things like telephone calls, guests, drinks, and so on.

On one occasion there was a problem with the use of the television in the living room, it was on all day and I got fed up with that! I had to say something.

Before I employ a new aid I have a long chat with her and tell her about my lifestyle. I make it clear that although I am informal in manner, I like to know what is going on in my house.

Of course, with a live-in aid, I have to accept that it is her home too. There are disadvantages, but I can see no advantage in lying in bed at night, unable to get out, alone in the house.

I always regard my aid's room as her territory and never enter uninvited, it is entirely hers. As regards her entertaining friends, this can be a problem. I have to have room to live my life, and she "does too. If I employ somebody from the local area I feel I can ask her to do her entertaining elsewhere, but with someone from far away. it can be more difficult.

Hopefully, if you pick a person you like, then there is a fair chance that you will get on with her friends anyway.

LENGTH OF SERVICE

With the live-in carer her length of service depends very much on the personalities involved. You can tire of someone before they tire of you, or vice versa. It would seem impractical to change too frequently, because the settling in process does take time, but also there is the possibility of stagnation.

If I had to say, I would suggest a year is probably about right. I feel that the more you can encourage the live-in girl to go away on her days-off the better. With one girl I had we both grew stale more quickly as she was not able to get away, whereas with another, who regularly went away, I had a much better working relationship.

Of course the situation is very different with casual workers, as I hardly ever see them except for their regular couple of hours a week. One of these has been working for me for two and a half years, and that is great. By their longevity they provide exceptional stability. Also, because they have an input into my home, live-in people can find new friends in them.

BOARD AND LODGING COSTS OF THE LIVE IN STAFF

Live-in staff become friends and their living costs tend to become part of life. I have never added it up. I would hate to quantify it. I am going to heat the water and the house, whether she is here or not. I ask the live in staff to keep an accurate record of their telephone calls, and they contribute to the weekly food bill, but otherwise I have to regard additional costs as part of the way of life I have chosen.

INSURANCE

I do not have any personal insurance in respect of being damaged by staff, but I do have a policy to cover my liability in case of staff accident or injury while at work. I have informed my insurance company of the staff's exact services, but do not have to pay an extra premium, it is within the household policy and comes under domestic servants.

COPING WITH NI AND PAYE

Basically, I have found this very straightforward. When I started my Dad showed me a bit, but now if I have a query I ask the friendly Mrs. Martin

at the Tax Office in Farnham. My particular system is a simplified tax. I only do it for the live-in staff. For the casual workers it is their own responsibility. They are required to show earnings on their tax returns, but the amounts are way below the taxable limit.

SPONSORING AUTHORITY INTEREST

My sponsoring Authority have never officially checked up on me. I am aware of an informal network which seems to have a pretty good idea of what is going on in my life. However there is no normal check up.

I am at present trying to get more money because I have not had a pay rise for my care staff for two years. Regrettably I failed to build an annual review into my original Care Proposal. No one has offered me a funding rise, the onus is on me to ask.

Le Court does not keep any sort of check on me either, indeed why should they?

The basic question must be, who should check up on me if anyone at all? If there was found to be some problem, who would actually take it up? Because there have not been any problems, I have never needed to ask. I am obviously coping, I am obviously responsible, so why should there be any element of supervision?

UNANTICIPATED DIFFICULTIES

One thing I am more aware of now than before I left Le Court is what I would call the social implications of sharing my house. Before moving-out I was very alert to the implications of care, care costs, working hours and things like that, but maybe I did not fully consider what it would be like living with somebody else. I had not thought much about this whole area. For example, what I would do if they wanted to entertain someone for the night, and so on? I had one person living-in who raised this sort of problem and it brought the issue very much to my attention.

I realise that society finds some things acceptable that I feel uncomfortable about in my house. So what right do I have to impose my moral standards on the aid? Quite a lot, I feel, because it is my house. I think I needed to be aware of these issues before they arose and perhaps I was not at first.

Another thing I have found since moving is that I am much more aware of being in the community. Transport and access are very important issues for me now. I travel around the countryside much more than I used to, and therefore a lot of the problems I encounter are those common to other disabled people in the community: hassles going down pavements, in and out of shops, pubs, cinemas, and so on. Not to mention the problems of , getting in and out of cars.

Because I travel alone in the car a lot, I am in difficulty if the car breaks down. I have a cellular phone, which is a luxury, but a lifeline too. It costs as much as a wheelchair, but then it could save my life one day.

REVIEW

Things have turned out much better than I ever expected. I felt in my heart that living at Le Court was probably only a phase I was going through, not the lifestyle I would choose for the rest of my life. I think I can build a better life in my own home. I see my present life as being normal. This is where I am. This is me and I am happy with the me I see.

Of course the opportunity to live in my own house brings responsibilities, and responsibilities mean ties. So in some ways I am more tied. For example at Le Court I could go to bed at 2.00 a.m. without a thought to anyone else. There was always someone there, but now I have to work out who is going to put me to bed. There are many things like this that I would not have worried about before.

I feel I have grown as a person. Being put in a position of responsibility has hopefully made me behave more responsibly. I know I am a more confident person. People grow through experience and I have had more experiences here than I would have done at Le Court.

Strangely I find I like being alone , I bomb around the house and drop things on the floor. It is my own home. I still can't get over it.



JOHN

John

EARLY DAYS

I broke my neck in December 1975 in New Mexico. I spent some time in hospital in the States and then flew back to complete my rehabilitation at Stoke Mandeville Hospital.

When the time came for me to leave hospital I did not have a home of my own to go to because I had been living in the States. The hospital administration insisted that I should go and live with my parents, but I felt this proposal was unfair and unreasonable. I was twenty six years old and had not lived with them for seven years. My care was too much for my parents to cope with. They were both ageing, and I knew that it would be both emotionally and physically difficult for them. In addition their house was very small and totally inappropriate for my needs.

A FIRST HOME

Fortunately some friends were willing to look for a different solution. They found a cottage to rent in the New Forest, an area I had never seen before. I left Stoke Mandeville on a Friday afternoon and was driven to the little bungalow which was to be my home for the next eighteen months. It was all very pleasant and olde worlde, but obviously I had not researched the move, and was totally naive. Nobody gave me any advice, information, or support of any sort. All I got from the hospital was a wheel chair, which arrived the day left.

One of my friends was a nurse. The other had no nursing experience whatsoever, but he devoted himself to looking after me and trying to get me going.

When I moved in an Occupational Therapist came to visit me and I asked her to make me some "plonkers". and straps, and to help me get some art materials, because I wanted to do some painting. That was the last I saw of her.

In order to give my friends a break I arranged to go to a local hospital twice a week for physiotherapy. It was pretty depressing because it was a geriatric hospital and all I could do there was sit around. I used to take a newspaper and a book to read in between the physiotherapy sessions. For income one friend worked and we shared my Disability Pension and Supplementary Benefits. I was not assessed for my Attendance

Allowance until I had been living in the bungalow for about two months. It was some nine months later by the time it came.

CHANGE IS FORCED

After about a year of this it became clear that things had to change. One friend wanted to go back to London to work, and the other decided she had had enough and wanted to go back home to Holland. So I was left in an awkward position. I knew months beforehand that the arrangement was inevitably going to break down and I had tried writing to all sorts of different organisations, communities and such places, to see if people would take me.

THE ONLY OPTION -RESIDENTIAL CARE

The last option was a Cheshire Home. These represented imprisonment and institutionalisation, all the things I had been trying to avoid. Another factor against them was that at that time I was not too keen on mixing with other disabled people. In the end I gave in and wrote off to the nearest Cheshire Home. It was sometime in March 1978. I wrote to the Head of Care, and she wrote back and said they were interested in my application and that I could come for a visit on April 6th.

APRIL 6TH, 1978

This was the day before our lease on the cottage expired! I was shown around the Cheshire Home and I decided to try and move there until I could find a better solution.

I returned to the cottage and contacted my social worker. I explained that my friends were not able to look after me any more, and that I wanted her to apply for me to live at the Le Court Cheshire Home which I had just visited. Meanwhile I had to go and stay with my parents in Wales.

Three weeks later I had a further meeting with the social worker. She explained that Hampshire Social Services would sponsor me at Le Court and that I was to go "on assessment" there in a month's time. We did not discuss any alternatives. I think we both realised it was either Le Court or nothing.

I did my probationary month and then after a two month period back in Wales, I returned to live at Le Court.

These two months living with my parents were probably the most difficult period of my life. It was virtually impossible for me to get out of the house and our relationships became very strained. It was inevitable in such a small house. During this time District Nurses came in every morning to get me up. Putting me to bed at night was left to my mother, brother or father. They all had jobs and did this in addition.

Amazingly enough, I think we grew stronger as a family through having to deal with my disability, despite the difficulties I presented. I can look back now and laugh at those times and even feel a warm nostalgia. When families are put through such adversity it can deepen the bonds.

LE COURT

I came to Le Court in August 1978, and remained there until December 1983. Five years. It had never been my intention to stay that long. When I arrived I made it plain to everybody that my stay was only temporary and that I did not see myself spending the rest of my life there. I had a two year period in mind I did not know how I was going to get out, but I was quite confident that I would find a way.

About a year after I arrived a group of us began discussing the future. Well actually, we were always talking about "ways out" right from the beginning but we did not come up with anything until 1979. In the summer of that year I went to Taylor House, a small hostel for severely disabled students in Oxford. Something came alive from that experience. A number of us went there separately, and we all felt that if four students could live in a house and be supported with unskilled care, so could we. From then on there was no stopping us.

PROJECT 81

This was the beginning of Project 81. Our small group set out to discuss other ideas with numerous other people, both in and out of Le Court. It was the beginning of a long and hard learning process.

At this time we tended to separate discussion of care needs from housing. This helped us to consider different ways of proceeding with each. So we never got caught up with orthodox solutions. We did not have any firm ideas how, for example, the care could be arranged, but we could see that just as the students at Taylor House received care, so could we.

We floated the idea that: if the authorities would give us a fraction of what they paid to support us at Le Court, we could find another way of meeting our needs. This was the first thing we really latched on to. We saw it as a wonderful idea. The general reaction though was that it was totally unrealistic!

FIRST STEPS

Our first step in search of support was in October when we met with some of the Cheshire Foundation Trustees. Two were encouraging, but the remainder were extremely sceptical. The fear seemed to be that we would establish some sort of premises that would bring the name of the Cheshire Foundation into disrepute.

Later that year, we talked further with the Head of the Le Court Home, and the Cheshire Foundation counsellor, Gill Corney. Both were encouraging. Gill was particularly supportive of the alternative living plans that we were putting forward. She agreed with our wish to live in the community and thought it was our right to do so.

EARLY IDEAS

Our idea was to have a home like Taylor House, where a small group of disabled people could live together. We thought Southampton might be a good location, because it was a big city with a university. We thought that might make recruiting staff easier as well as having some "life".

FORMAL RECOGNITION

Early in 1980 Peter Wade, a former resident of Le Court, joined our discussions, and we began to meet informally with Ann Parkes, the General Manager of the Cheshire Foundation Housing Association. We asked the Le Court Residents' Association to Support an application for our formal recognition by the Home's Management Committee. In April 1980 this was granted. Project 81 was established as a Housing and Care sub committee of the Le Court Management Committee. We had our first official meeting in May 1980. By now we had decided to work with Ann Parkes and the Housing Association to get our group home.

A WARNING

Later that year we met Ken and Maggie Davis, a disabled couple who live in their own flat in Nottingham. They warned us against the group

home idea as it had been something that they had thought about some five years previously, and found there was a real danger that it would end up just another institution. These warnings remained at the back of my mind from then on. However we still thought of Taylor House as a model and felt that what we were trying to do would not become another residential home because the people involved were aspiring to something different. Also, I could not see any other way of getting a home through the Housing Association, as the cash guidelines appeared too restrictive. I did not consider Local Authority housing because I did not think they would consider me. Somebody else at Le Court had recently been turned down by the Local Authority on the grounds that they were already adequately housed, and it seemed that if I went that way I would have to wait forever.

WESTWOOD ROAD

Almost immediately after we started looking for property in "Southampton a suitable house in Westwood Road came to our attention. We set about trying to purchase it through the Housing Association: Exciting and hectic days followed as we worked on the planning and adaptations. I even went and lived in the area for a week to familiarise myself with the neighbourhood. All this was a learning process and I think each of us was slowly putting together what were at first just hazy ideas of alternative ways of living.

EARLY EXPERIENCES OF THE STATUTORY AUTHORITIES

We began meeting with the Health Authority in the area as we knew our plans would involve them. Some of them thought our scheme was not financially viable and that there was no way we could get the support to cover the amount of care that we needed. They only thought, if care support in terms of medically trained staff. Some of them told us that many of our demands were quite selfish and unrealistic, others just thought that we would not be able to cope.

We worked hard at selling our ideas to these people, attending numerous meetings over a long period. It was tough having to go to such lengths to promote something which we were all sure was going to work but we needed the support. After each meeting it always seemed to take so long before we got to the next stage in our negotiations. Fortunately we did not give in. Right from the start Peter Wade insisted that we should never compromise on the original vision. We never did

really. We stuck to our guns right. the way along and in the end, we did achieve our objective.

THE FIRST SETBACK

Westwood Road fell through in October. Somebody else bought it while the Housing Corporation were still considering our application. That was a shock. It had represented in a physical form "the vision". To lose it was a real blow.

We renewed the search in Southampton travelling there and back, week by week, month by month, without any success. We must have looked at over 50 properties, and were inundated with houses from the estate agents which we had to sift through. It was a demoralising period, and I do not know how I would have kept going had I not had the idea of travelling back to the States.

BACK TO THE USA

I had wanted to return to the United States for a long time, and had already begun to find out about the American Centres for Independent Living (CILs). In the Summer of 1980 a friend suggested I apply for a Churchill Scholarship to enable me to make the journey. I applied in September, but this was unsuccessful. I was very disappointed and tried to find another way of raising the money. Then in February 1981 the Overseas Manager of the Cheshire Foundation contacted me to say that the Foundation had decided to pay for two air tickets. I was half way there. All I needed was to raise enough money to cover the living costs for myself and my care attendant for six weeks.

From February until I left in August my time was mainly devoted to this project.

ASSESSMENT

But before that came a bit of "business". One of our meetings with the Health Authority had come up with the idea that a colleague, Philip Scott, and I should spend a week in the Independent Living Bungalow'. at Odstock Hospital. This was mainly because they were very suspicious, indeed sceptical, of our proposals and felt it was necessary for us to prove that we could live that way. So in May, shortly before my American trip, Philip and I went to Odstock for a so called "Independent Living" week.

We were a bit insulted about the idea and the way it had come about. but we went along with it because we thought it would make the sceptics happy. We knew we never needed to do it. I guess this was one of the compromises that we did make, even though we knew that in the end we were not going to let the ball go completely into their hands.

In fact we had a lot of fun, our main problem was keeping our attendants in beer money! Also, we met a very helpful Occupational Therapist who has maintained an interest in our work and has been extremely valuable to us. This relationship still prospers and was a most positive, if unexpected, outcome.

OXFORD STREET -SOUTHAMPTON

At about the same time a large property became available in Oxford Street. It was planned as a group home for three people, but neither Liz, one of the other intended tenants, nor I, was madly keen on the house. Soon after this Liz decided to go her own way. I felt that I was not going to go ahead either, so I pulled out of the project just before going to the States. I decided I was not going to live there and for me that marked the end of the group home idea. Philip took the scheme on.

In truth the whole of 1981 was dominated by my trip to the States. This journey to St Louis, Berkeley, Albuquerque and JW Boston, convinced me of one thing above all others, and that was ..that I had to go ahead and get this "living in the community" done.

The trip was an incredibly uplifting experience. Everything I dreamed of, everything I thought of, there it was going on in front of my very eyes. It cemented my approach to living independently and destroyed quite a few fears that were floating around in my mind. I knew for sure there was nothing to be afraid of.

PETERSFIELD

By the time I returned to England Liz had already found her bungalow. This encouraged me to pursue my searches. I felt that if the Housing Association could help Liz in Cowplain then they could help me in my chosen area. Cost guidelines meant it was going to be harder to find a similar property in Petersfield, but I had decided that was where I wanted to be. I started looking for properties and put my name down on the Local Authority housing list.

A LEAN PERIOD

As 1982 and then part of 1983 passed without my finding any suitable properties, I incurred increasing criticism. Many people thought that I was not taking moving out of Le Court very seriously, and they suggested that I did not really want to leave. That really bugged me. I knew inside me what I wanted to do, but everyone seemed to think I was stalling, or being unreasonable in not accepting any old property. There were more pressures when Philip found his bungalow.

He was able to find a place so quickly because he could buy privately. People did not see that, and it annoyed me, as they questioned my commitment to moving out. I was pleased for Philip's sake that he had got his place and wished him well. Besides, I could learn from watching how he organised his care, the adaption of his property, and everything else he did.

FRESH DEVELOPMENTS - CARE

1982 saw the growth of the Project 81 group into Hampshire Centre for Independent Living (HCIL). This aimed to be a more broadly based self-help group for disabled people in Hampshire.

In May HCIL invited a team from the Hampshire Social Services to attend a discussion on Independent Living. That is when I met Lynn Kear, the local Occupational Therapist. Soon after that we decided to put together a Care Proposal for me, even though I did not have a house. I knew that Liz had done the same thing. Further, I was aware that Philip's proposal had taken nine months to receive approval. So, house or no house, I decided it was time I presented a proposal to the Social Services. I had been involved in talking to Liz's Social Services, and had helped Philip with his Care Proposal, so I already had a good idea of how to proceed.

WORK ON MY CARE PROPOSAL

My main aim was to show the authorities, in a presentable and appealing way, how I could live independently in the community. I worked very hard on it. Mostly on my own with comments from my colleagues.

I was building on Liz and Philip's experiences. My vision was coloured by what they had done, but at the same time I knew that the details of

my proposal were going to be quite different. I tried to imagine a system that would work for me. I realised that I was not going to be absolutely sure until I had tried living with it, but I had a pretty good idea of the kind of life I wanted and the Care Proposal was my way of asking for the help needed to achieve it.

THE DETAILS

My concern in preparing the proposal was to demonstrate that I really needed the amount of care that I was asking for. I split this up into three categories:

the physical care, which is getting up, going to bed, and some additional attention;

the domestic care, which is cleaning, shopping, food preparation, washing up; and,

social care, like driving to places, visiting friends, attending meetings, conferences, etc.

I wanted a live-in care attendant, but did not necessarily want him or her to be the person who was to do all these things for me.

I never gave any details as to how I thought the duties might be arranged, the only things I described were the general tasks that had to be fulfilled. My idea was to have a live-in care attendant, who would perform some of these duties, but also to employ several back-up carers from the local community. I suppose the thing that was running through my mind was to have more than one care attendant to spread the load. Not the more the merrier, one can have too many, but as long as I had three, and an emergency list of people I could call on, I thought that was plenty of back-up.

In March 1983 I presented my Care Proposal to the Social Services, and in August one of their senior officers rang me to say that I could go ahead with it. It took five months to be approved.

FRESH DEVELOPMENTS -HOUSING

As far as housing was concerned the outlook continued to look bleak. I had submitted a bungalow in Petersfield to the Housing Association at the end of 1982. It fell through before it even got started. I was still on

the District Council housing waiting list, so I had that hope, though I never seemed I to get very far in my few meetings with the Housing Officer. Then, in the summer of 1983, I found out that there was a new Housing Officer, so I thought it would be a good idea to arrange to meet him. Within six weeks the new officer offered me a flat.

MY FLAT

I went to see the flat. It was damp and cold, and very difficult to see how it was going to be adapted to make me feel happy. I cringed and wondered if it could really be what I wanted.

Despite my fears, I accepted it almost immediately. The area seemed alright, reasonably flat, near the shops, the pubs and the library. I was able to keep the same doctor and dentist from Le Court, and, as I had shopped in Petersfield many times before, I was familiar with the town. Additionally a disabled friend already lived in the same road and I knew that if I had any problems I could always consult him. His house was similar to mine, so I could also talk to him about adaptations and in fact he proved to be of enormous help to me.

GETTING THE SHOW ON THE ROAD

The necessary structural alterations were quickly established. I listed all the things I wanted to have done, and after I had signed the tenant's agreement the Works Manager came to see me and we agreed the work.

In the early discussions I was concerned to hear talk of phasing the building work. I wanted it all done at once so that it would be ready when I moved in. I did not want to have building work always going on around me.

I was told I would have to let it be done in stages, but I was quite adamant that this should not happen. As I understood it they intended to pay for one adaptation, then I would move in.

Later on, they would fund another adaptation. All of which could have gone on for a couple of years. I feared being stuck with the place half adapted. The arguments were not about what needed to be done, but how. To me it seemed to make a lot more sense to do all that was necessary in one job. Fortunately this view was eventually accepted.

PAYING FOR THE ADAPTIONS

It took over two months to put a package together to pay for the adaptations. This consisted of grants from the Social Services, the Environmental Health department and the District Council's own Housing Department. Wessex area Health Authority supplied a hoist and rail for my bedroom and, after a year's wait, a "Steeper" environmental control system.

THE RENT PROBLEM

When I signed the rent book I had been given the impression that the rent would be paid by the DHSS. At the time I did not know enough about the Social Security system to be able to assess whether this was correct, but it seemed right that they should pay the rent while the place was being adapted, as they would be paying it when I moved in.

The Housing Department followed this matter up with the DHSS and where they did not get satisfaction at the local level, they pursued the matter with the local MP and subsequently the Secretary of State. The DHSS insisted that as I was not in residence they could not help and that the rent problem rested with, the Housing Department.

I found myself caught between the DHSS and the Housing Department. All the way through October there was increasing pressure on me to move in, in order to try and get the rent paid, but I was not prepared to move until the flat was ready.

When it became clear that the DHSS would not pay my rent, a meeting of all the interested parties was arranged to try and resolve the issue. The Housing Department felt I might be able to pay off the debt myself, or get a charity to help. However no one was prepared to pay so we spent the time beating around the bush.

The pressures over the rent arrears were a great worry to me. The debt and the aggravation concerned me! Of course I wanted to move in and get the rent paid. Of course I wanted everything in order. The last thing I wanted was to generate ill-will. But I felt all this was out of my hands and I was not prepared to move into a building site. It would have been impossible to cope in such a situation. I had learnt that from Liz's experience.

The pressure on me to move in increased. It was hinted that the mounting rent debt might force the Housing Department to give up the project. However, once the work started on the 1st of November, this pressure subsided. I think people realised that the whole flat was being taken apart and that no one could have lived in it during this time.

WORK BEGINS

Despite the fact that I had asked for the ramp to be built first, so that I could get into the flat easily, it was done last. This was annoying, as every time I came to look around I had to be bounced up two big steps. This meant that I had to be in my pushchair rather than my power chair, and this restricted my mobility. In fact the ramp was not built very well when it was done, and had to be rebuilt.

Apart from the ramp, the only other structural error was the positioning of some of the power sockets. These were the right height, but difficult to get at in a wheelchair because they were too neat - the corners of the rooms. Other than that, I was very pleased with the way things worked out.

FURNISHING MY HOME

All this time I was sorting out the household fittings; organising decorations; thinking of care routines; and generally preparing for my new life.

I had no help with any of the furnishings and had to provide these myself. There is a grant available from the DHSS towards these but I was not eligible for this, as I had just over £500 in the bank. We managed to raise £400 from various charities after writing 72 letters, but the bulk of things came as gifts from family and friends. "

KITCHEN PROBLEMS

Just before I moved in a problem arose over the Environmental Health grant. I was told that my kitchen did not qualify. I had already gone ahead with the fitting-out on the basis of a verbal agreement and now the officials told me that they could not support it. They wanted to withdraw the grant on the grounds that they felt it was not a disabled' kitchen, even though it was the one most suitable for my use. I think the real problem was that I was the victim of the cutbacks. Later on, after I had protested vigorously, they agreed to pay a proportion of the cost. I had to find the rest myself.

ADDITIONAL COSTS

Throughout the six weeks that the work was being done I was visiting the house at least twice a week. This meant hiring a vehicle, paying for the petrol and finding a driver.

Also, the various expeditions to collect and deliver furniture had to be organised and financed. In one week I remember covering a distance of 300 miles just in the local area!

There was also the cost of phone calls, and other correspondence. And, for the two weeks before I moved, I paid the attendant who was helping me £50 a week.

All these expenses had to be met from my limited savings.

THE MOVE

When the time came I was able to call on a lot of help from friends who packed boxes for me, and transported things. In fact there were two momentous trips when everything was moved.

My attendant moved on the Sunday night, and I moved in on the following Wednesday, the 11th of December. There were no carpets, boxes were piled everywhere, and the whole place was covered in dust

After a few days, we realised we were not going to be able to live without carpets, as the dust was getting everywhere. I arranged for someone to do the carpeting over the second weekend. That made an incredible difference.

HOME

Despite the difficulties, I felt at home straightaway, though looking back at it, there were certain stages along the way when the home became more of a home. Putting all the carpeting down was the first step. Then getting rid of all the boxes from the middle of the living room, and then when I got some lamps put up.

It didn't take very long to establish myself and with my friend living so near, many other details, like dustbin day, milkman, and so on, were easily sorted out. In fact, the weekend I moved in I asked my doctor to come and visit me to see my new home, which was just as well because

I had some problems. I am quite sure this was the result of all the anxiety and the build-up to moving in. Fortunately everything soon sorted itself out.

MY FIRST LIVE-IN CARER -LOTTE

Lotte was my care attendant throughout this period of change and she was very important indeed. I had met her earlier in the year when she had been working at Le Court. She had agreed to come and help me move in and set up home. We had quite a good understanding and I had warned her that there would be lots of pressures, responsibilities, and long hours ahead.

All in all, although there were difficulties and pressures, we got on OK: as we were able to talk things through, and Lotte is a very tolerant person anyway. She stayed with me for six months, so she really established me. I will always remember her because of that particular period. She was a part of something that was very special. She realised how important it was and how much it meant to me. She understood what was happening in my life. It was my own home, my own place. She truly appreciated the significance of the move.

At first Lotte had to care for me as well as carrying out all the other household chores and the business of building up a new home. I had not yet organised my other carers and we were still trying to find things, unpacking boxes, and so on. I think that if we had not gone to my parents for a week at Christmas it would have been too much. That was a good holiday for us and we both had a good rest.

BEING PART OF THE COMMUNITY

Until I moved out, I had never realised how isolated I was in Le Court. It was a very remote existence. The routines and timetables dominate and hide what is happening in the real world. In your own home you have to be much more yourself. You, as a person, are much more exposed. You cannot hide behind the organisation.

Now I find that my social contacts are extending and I feel part of Petersfield. People drop in on me all the time, it's an inviting home in an ordinary road. It is a lot easier to go to the town centre than I had imagined it would be, and if I need any help once I am there, I can usually find it.

My neighbours have all been very helpful. There are four or five I can call on who would willingly come and make me a cup of tea, or get something out of the fridge and put it in the oven.

I think there was some jealousy when I first came because I was a single person, and I was moving into a flat that was big enough for a young family with children. But now, as people have got to know who I am, and what I am doing, I feel most of the barriers are broken down.

Perhaps some people may be critical of the financial help I am getting from the Social Services, thinking that could go to supporting some old people, or something else. But it is not my fault that there are limited resources allocated to Social Welfare and that those in need end up fighting each other, that is the consequence of a deliberate political decision.

VALUE FOR MONEY?

As for my response to someone who questioned the value of adapting my house I would point out that a special building would have cost a lot more. The fact is that this house has been adapted in such a way that able-bodied people can still live in it after me. Of course I would always like to see it kept as a dwelling for disabled people, because there is such a shortage of suitable dwellings for them anyway, but it is not exclusive. This property can easily revert back to the general housing stock.

Another point is that the "giving" is not all one way. Apart from employing people, I am an asset to the community in other ways. Society at large is able to benefit. I am able to share my experience with other people. Not that I think I have to do this to justify my new position. I do it because I want to.

OK, I might be regarded as elitist and somebody who knows the ropes, and that is why I got where. But I think: my doing it is only a stepping stone for other people who now might think of trying something similar.

Another thing, if I had not done this for myself, where would I be now?

REFLECTIONS

Overall my life since my move has exceeded all my expectations. I do not regret the change in any way. There was a part of me which feared I could not cope with being by myself. I was a bit worried that I might

have a bad spasm or something and fall out of my chair, but I have put all that behind me and I really enjoy the times when I am alone. Even lying in my bed I do not get worried, as I have my alarm system. It is quite a nice feeling actually being by myself.

The quality of my life has changed enormously. It is to do with control and choice. I can be myself. I do not have to worry about conforming to other people's standards. It is my house and I am the boss. I can choose what I do.

I feel secure in my own home. It is mine, and I can close the door behind me, close the curtains at night, turn the TV on and just wade into the bliss of being in my own place.

I have left behind the anxiety of being part of a clinical-smelling, urine-smelling, bells-ringing, system, with all the petty jealousies and manipulations that went on there.

It is so peaceful in my own home, even though there are pressures and a constant challenge. That challenge will go on because, whether I like it or not, I live with the thought that for the rest of my life I am dependent on other people. I am always going to have to be employing people, changing them, and so on.

I have my experience in the New Forest cottage years before to compare things with. This is a lot better, less of a struggle. I have the ability to pay for what I, need, and I am not relying solely on the goodwill of other people. I am not dependent on so few people.

If I had complaints they would be about money. Lack of money is very restricting. More money would give me a bit more freedom, more flexibility, and I could feel free to use more care attendants as I need them, and to pay them better.

At present if I have to go away to a conference it is tough asking one person to cope with all the travelling and care work involved. It would be far easier to take two.

As for whether I have changed as a person, I do not know. I probably have, but it is something I do not think about. I have certainly changed from what I was like when I was at Le Court, but I think: that was because I changed as a person during my time in the Home. That was a matter of necessity: I had to go out to the pub regularly and do those

sorts of things because they were all ways of expressing individuality. Now I do not feel the need to do that so much, I am quite content to be at home.

I think I became somewhat introverted at Le Court, as I was so intent on defending my privacy. Now this is not something I have to worry about. When I first came here I could hardly sleep, just the excitement of being in my own place again. Instead of just one tiny room in which I had everything -my work area, my office, my living room, my bedroom -now I have five different rooms. It is really quite extraordinary. One of the things that amazes me is how much more I can do now. I am not confined by tea times, and going to bed times. I really can work until I have finished.

I still resent having had to go into care in the first place and I wish I had left earlier, but that is easier said than done!

INDEPENDENT LIVING - THE PRACTICE

CARE DEVELOPMENTS

To begin with I was able to get by with a very tight organisation of three people. Mainly Lotte, backed up by two local people. It was almost an ideal set up. I would like to have a similar one the whole time.

Later in the Spring, I went through quite a difficult time. Perhaps this was a reaction to the uncertainty and stress of the previous six months, or it could have been the fact that Lotte was leaving and I was going to really become independent.

There followed a time of an amazing number of changes. I had six different main care attendants in six months! I purposely put myself through this insecure period and it taught me that I can survive. I can organise something even at the last minute. The ability to cope with this gave me real confidence. During this time there were two ten day periods when I had no main carer at all! I had people coming in who had never worked with me before. I never knew how it was going to work out from day to day. It was a challenge, I relished it. This was a great experience in terms of understanding my care needs and how I relate to them, but, I must say that I would not like to live like that for longer than ten days! Indeed, I keep my carers for much longer as a rule!

Sometimes with attendants you look forward to when they leave, not in a nasty sort of way, but you look forward to a new challenge, the variety, the change, but you always know you are going to have to re-establish your routine again.

The care aspect of my new life has worked out remarkably well. I now have a lot more confidence and have not really had anybody who has been negative, or any real hassles. There have been some minor incidents and personality conflicts here and there but overall the theory of the Care Proposal has worked well in practice.

DAILY ROUTINE

At present my live-in attendant works a five day week and is off for two days. He or she gets me up three days a week, and puts me to bed four nights a week. For the rest of the time I am covered by people coming in on an hourly basis. However these details are not rigid. I like to feel that I am able to change things. When people come to work for me I make it clear that things are flexible.

If my care attendant goes away for the weekend I have to find someone who can stay with me, or come and cook meals. I can usually think round two or three people, and ring them a couple of weeks in advance. It is something that I am constantly aware of even though I have a well organised schedule.

It is quite a hassle having to constantly organise care. If I need to get cover, it means a lot of phoning around. Every week I look ahead to next week and think: What will be happening then? Which days does my care attendant have off? What have I got covered?

My system works well for me and I will probably stick to it, because I find it is easier to have someone living in. I can be flexible about the time I go to bed, more so than when someone is coming from outside to put me to bed.

THE ENVIRONMENTAL CONTROL UNIT

I now have an environmental control unit, but it took a long time to be installed. A year. It is a comprehensive unit. I always have it in bed with me. It has an alarm on it so I feel safe. I do not mind sleeping by myself, as long as someone is around when I need turning in the morning.

The unit is very convenient to make phone calls on as well. I have a bank of 10 pre-programmed numbers, my neighbours, my doctor, things like that. I can also make dialled calls and answer the phone from my bed.

STAFF HOLIDAYS OR SICKNESS

My live-in carer has holiday entitlement according to the Witley Scale, which is one week for every three months worked. I cover the time of his or her absence with casual labour. So I pay double during the holiday. Similarly, if my live-in carer is off work through illness, then I would call in some of the part-time people. This extra cost was not built into my Care Proposal effectively enough. I did mention the idea of sickness and holidays, but there were no figures put down. I have learnt from this and make sure it is built into all the Care Proposals that I help other people prepare for themselves.

Finding someone to come in at short notice means calling around friends, or casual staff. I have no formal arrangement with the local Care Attendant Scheme. I have met the Organiser a couple of times and she has said that if I ever get stuck I can get in touch with her, but I do not think I will ever need to do so, as I have my own emergency list.

If I am sick during the five days when my full-time helper is working it is not too bad because he or she is in the house anyway. However, outside those days, I would probably need somebody to come in during the daytime and would try to use my regular helpers for this.

MY HOLIDAYS

If I go away on holiday I take my live-in carer with me, and sometimes, if I am away for a while I take somebody else as well. It depends on individual arrangements really: who you take, where you are going, what you are doing. For example, if I am paying for the holiday then I would take a helper who has agreed to be paid less than the full amount. This is all I can afford and is the only way I can take a holiday.

Ideally I need two people with me to be able to go away on holiday, and of course I would like to be able to pay for two people. But that isn't possible on my income.

FINDING STAFF

All my live-in staff searches have been through word of mouth.

I have never used Job Centres or newspaper advertisements. It is all through friends, previous contacts, current care attendants, and so on. One day I may well have to try other methods, but so far this has been sufficient. I have not had trouble recruiting casual people this way either though I find the evenings are slightly harder to fill than the mornings.

LOCAL CARE STAFF AGENCY

At the moment I do not feel there is a need for a local care staff agency. I think I am perfectly capable of identifying possible staff. There again, if something like that existed, I suppose it would be helpful to some people. In truth, the more ways of finding potential staff, the better.

CARE AGENCY: THE SPINAL INJURIES ASSOCIATION

I have used the SIA Care Attendants from their Care Attendant Agency. On both occasions only for a limited period and of course I paid the Attendant. I helped set up the agency and wanted to have direct experience of it. This source of Care staff is one that I would always have at the back of my mind, but I would be reluctant to use it often because there are other people more in need than I am. It is definitely a very worthwhile resource.

CHOOSING STAFF -THE INTERVIEW

The selection of an employee is based on a gut feeling in the end, but I have a list of questions that I use to help me approach people, and screen them. I want to find out as much about a person as possible, and at the same time I want to let them know a bit about me. I can usually sense what sort of a person they are by noting the things they ask questions about. I observe their reactions to things I say and can soon tell if they are really interested and eager about the job.

For a live-in carer I look for somebody who is responsible⁷ trustworthy, respectful, flexible, physically able to cope with the lifting involved, able to drive, and preferably able to cook reasonably, although I can always help people with that. I also like them to be self reliant and able to get on with their own lives.

With part-time people I am more tolerant. You are not going to find the abilities I mentioned in everybody. Each person is different, some are more reliable, some are more responsible, clean, tidy, and so on.

AGE

Up until recently my live-in staff have been aged between eighteen and twenty five, but the present one is thirty. I do not think age is very important.

PREVIOUS EXPERIENCE

If somebody has done care work before, the training process tends to be quicker, but previous experience can mean people come determined to tell me how things are done. It is usually better if possible carers have had no previous contact at all with care work, so that they start on the basis that I am responsible for myself. This applies particularly to live-in staff.

TRIAL PERIOD

When somebody comes to work for me, even though I may have known them before, they have a month's trial period. This provides a safeguard for both parties. The situation has never arisen, but if somebody did not get on well here, I think I would try and agree to make it even less than that. If somebody is not very good then hanging around too long would not be helpful, because it would make life unpleasant for both of us.

STAFF: LENGTH OF STAY -LIVE-IN

Six months I think. Maybe a bit longer, depending on the type of person, and how well you get on. But I find six months a happy medium. Anything less than six months can be a bit too changeable, although change and variety is quite nice.

Anything more than six months, then obviously that person needs to be fairly amiable.

LENGTH OF STAY -CASUAL STAFF

Some of my casual staff have stayed longer and it is no problem because they only come when I need them and do not stay in my home. I have had two for eighteen months. There is no reason why casual staff cannot stay longer, provided they want to, and that I am happy with them.

LIVE-IN STAFF COSTS

The live-in staff and I share the cost of food. He or she also pays towards heating, and wear and tear, and so on. I do not think this covers the real cost, especially in winter when the heating is high, but even if I was living by myself I would have the heating on anyway. Obviously phone bills are something we detail separately.

COPING WITH NI AND PAYE

My live-in carer and I usually deal with NI and PAYE together. I am quite happy as long as I know what is going on. I get him or her to fill in the forms and then I check them. It is a lot easier getting people to learn how to do it for themselves, and it saves them an idea about something they probably never have anything to do with normally. At the beginning it was confusing, with things taking more time than necessary. Even now it is a lot of paperwork. It takes 20 minutes or so to fill in the forms. Every now and again we might need to look up something. I have a number of helpful documents, also if necessary, I can ask a colleague, Liz, for advice.

INSURANCE

I have an addition to my home insurance, which covers me for negligence if someone is working for me, and also protection for myself from other people and vice versa, for injury. It is an extra premium of £20. Something else I didn't put in my original Care Proposal!

RELATIONS WITH SPONSORING AUTHORITY

My "case" was "reviewed" for the first time earlier this year by the Social Services. It was done through my Occupational Therapist. I was formally invited to discuss a number of aspects of my needs and their funding. It was a good opportunity to show my Occupational Therapist many of the things I had missed in my original proposal, like holidays, sickness, etc. was able to introduce these onto future calculations. Hopefully this procedure is going to be repeated every year.

Le Court, the body responsible for transferring funds from the sponsor to the rig authority to me, have no other role in my life. They just handle the money and that is it. Obviously they retain a friendly interest but nothing else. They respect my privacy.

My arrangement with Le Court is like an agreement between two people who know and trust each other. Their role is necessary because of a law

forbidding Social Services departments from making direct payments to clients. It is all rather silly really and everyone concerned would like to see a change in the law. In the meantime I would not have been able to leave residential care without the willing, co-operation, of a body like Le Court.

At the risk of stating the obvious, when given the opportunity, we see that:

Each person is different.

Each plans and goes about things differently.

Each is gloriously individual, and very human.

Each has his/her own ideas and is quite capable of putting them into practice.

Nonetheless their experiences have some common characteristics:

Each decided for him/herself what he/she was going to do in the light of all the information, advice and experience available.

In particular:

- 1 These people were highly motivated.
- 2 They experienced extreme difficulties.
- 3 They enjoyed the active and continuing support of:

A their friends and peers, as in Project 81 and Ken & Maggie Davies, and,

B a few "like thinking" representatives of statutory and charitable organisations, such as the Head of Care and the Head of Home at Le Court and the local Occupational Therapist.

- 4 They became experts in what they were doing.
- 5 Each thought long and hard about the life he/she wanted.
- 6 The lifestyle they chose, though "normal", was for reasons beyond their control, hard to attain and remains to this day, hard to sustain.

To round off some details:

The last member of Project 81 left Le Court in 1984. The Oxford Street project persisted and opened as a home for two disabled people in the Summer of 1985.

Finally:

Project 81 naively believed that once they had "done it" the flood gates would open and new horizons and opportunities would open for disabled people.

Sadly this is not the case and indeed one would have to say that we live in an even harsher climate today. One in which even the hard-won gains of Project 81 are threatened and questioned. '

Meanwhile the Caring Professionals and Concerned Charities, by and large, persist in determining how and where we live; who is helped, and how.

It was as if Project 81 had never happened.

BUT IT DID. WE DID IT.

Let us take pride and inspiration from that.

The struggle goes on.

THE END