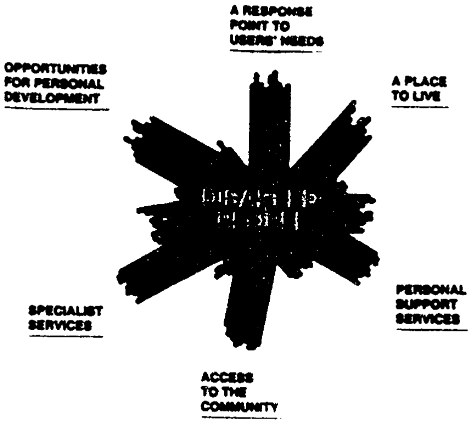
WEST ESSEX

Report of the

'Living Options Enquiry'

Into the needs and expectations of highly dependent physically and sensory impaired residents of West Essex



Enquiry commissioned by the West Essex

Living Options in Practice Team

&

Conducted by Ruth Haigh

(Oct. 1991 - April 1992)

COMMUNITY LIVING DEVELOPMENT
TEAM KING'S FUND CENTRE

THE PRINCE OF WALES'
ADVISORY GROUP ON DISABILITY

Preface

West Essex 'Living Options in Practice' Project

The West Essex Living Options Practice Team came into being as a result of the local Joint Planning Team's efforts to develop a range of support mechanisms to enable people with physical and sensory disabilities to make choices about their individual lifestyles.

West Essex was adopted as a pilot district in the King's Fund Centre's 'Living Options in Practice Project' and its Practice Team chose to concentrate much of its effort on identifying the needs and expectations of the most highly dependent residents in the area.

The Living Options Enquiry was commissioned to discover and record the 'consumer view' through a series of interviews in a variety of settings and circumstances.

The following report sets out the findings of the survey with observations and recommendations offered by the independent researcher involved.

The 'Practice Team commend this report to all those concerned with creation and delivery of enabling services in West Essex, and beyond, as a valid basis future development.

Living Options Team

The core membership of the team is drawn from the original Joint Planning Team, plus a number of additional invited members whose special expertise has been engaged to broaden the teams focus. In the course of the 'project team members have been:

Geraldine Butcher,	
Margaret Barrie,	
Philip Cunningham,	
Peter Lainson,	
Jenny Holding,	(until May 1991)
Di. Kirk,	(from May 1991)
Jo. Brennan,	(until May 1991)
Shirley Eden,	
David Rosling,	(from August 1991)
Rob. Griffiths	(until August 1991)
Georgina Parkin	(until August 1991)
Nick Macarthy,	(from November 1991)
Tracey Buckingham,	(between Aug.& Dec.1991)
George Howard,	(from Dec.1991)
Terri Gray,	

Acknowledgements

The West Essex Practice Team are indebted to all users of existing services who have given their time and energy with enthusiasm in the course of the enquiry and made possible the valuable report produced.

We wish to congratulate Ruth Haigh for having conducted the survey with such admirable sensitivity and effect, for her patience with the team and for an illuminating report which fulfils our expectations so thoroughly.

We wish to thank Christine Atlee and her colleagues for the mass of secretarial and administrative work which has been invested in keeping the 'Project, and the team, so well ordered.

Our thanks go to Diana Twitchin and Barrie Fiedler, as Co-directors of the overall Living Options Project, who have provided a wealth of information, advice and support throughout our endeavours.

We are grateful for the grant support provided by West Essex Joint Consultative Committee and the Community Living Development Team King's Fund Centre in partnership with The Prince of Wales' Advisory Group on Disability. Without their financial aid the survey and this report would continue to be a pipe dream.

Help throughout the project from John Reading of Anchor Press has been greatly appreciated.

Contents

1 Background

The objectives of the Living Options Enquiry were:

- To identify the particular needs of the most highly dependent of disabled people and their carers, both as individuals and as family units.
- To identify the role users want to take in the development of services.

To this end the West Essex Living Options in Practice team appointed a consultant to formally enquire into the views of a number of disabled people living in the area about what services matter most in frustrating their realistic ambitions, to report the findings to the team and to make recommendations as to how the users can be involved in the planning of the services.

2 Methodology

It was recognised that in the time available a scientifically representative sample of disabled people in the area could not be located. However it was considered that by including people in all ten year age bands from 16 to 64, with a variety of disabilities, who lived in residential or private accommodation, some of whom had experience of Pine Respite Care Unit, and that by holding discussions with approximately 40 people, a variety of experiences and views would be obtained to give some picture of the needs and aspirations of disabled people in West Essex.

The study was conducted with highly dependent disabled people since these people are felt to represent the critical criteria, since if their needs can be met those of less dependent people should, by definition, be able to be met.

Identified individuals were contacted by letter to explain the project and to request their participation. The letters were followed by telephone calls to arrange a day and time at the convenience of the participants.

Discussions with most people were carried out in their own homes or in their residential accommodation whilst others chose to meet at Pine Respite Care Unit. Some people chose to have the discussion alone, others with their carer present, and the condition of some people was such that the discussion was conducted with the carer but with the individual present.

A checklist was prepared by the consultant as an aide-mémoire to ensure that the same topic areas were discussed with all participants. The topic areas covered were; housing, aids and equipment, wheelchairs, support for personal care, domestic support, health care, respite care, transport, education, employment, leisure, social activities, religious activities, holidays, information provision (eg about benefits, available aids) and personal development.

Before the discussion began the consultant again explained the project; that the Living Options Team were interested to find out how people would like to live their lives, ie. what needs they had, and what services or support they felt they required to achieve this, whether people had been able to participate in choosing the services they had received so far, and whether and how they would like to work with professionals in the future to plan their service needs.

The discussion was often led by the participants so that the interview did not always follow the same pattern and the consultant often had to enquire into the responses to obtain further relevant information or comments.

As the responses were taken at face value it should be remembered that people may forget or misunderstand or be confused about which group of professionals they were/are in contact with. The consultant's task was simply to record what people understood their situation to be, how they would like it to be, and whether, and how, they would like to be involved in the planning of the services they receive.

3 Summary of findings

Discussions were held with 48 individuals, 20 men and 28 women. In the following age groups:

16 - 19	1
20 - 29	11
30 - 39	9
40 - 49	9
50 - 59	12
60 - 64	6

People with the following impairments or diseases were represented; Spina Bifida, Cerebral Palsy, blindness and partial sight, spinal injury, stroke, epilepsy, spinal muscular atrophy, the effects of the removal of a brain tumour, Charcot Marie Tooth Disease, Parkinsons disease, Friedrich's Ataxia, rheumatoid arthritis and Multiple Sclerosis, some participants had more than one impairment or disease.

A breakdown of people's living arrangements showed that:

17 people lived in their own homes, some of which had been bought from the Council,

12 people lived in Council houses or flats,

1 couple who were both disabled lived in Housing Association property

and 2 people were in hospital awaiting sheltered accommodation.

14 people lived in residential accommodation, Chigwell House.

21 people lived as a couple, with the majority being husband/wife, though 2 were brother/sister and 2 mother/daughter arrangements.

9 lived in a family group ie as a mother or father or as a son/daughter

and 4 people lived alone.

The main issues identified by most individuals were; housing, physiotherapy and transport.

3.1 Housing

Housing was the major concern for the majority of participants. The points raised could be divided into issues about moving house and/or the provision of downstairs extensions and/or adaptations such as stairlifts, hoists and ramps. The responses of those who live in residential accommodation at Chigwell House have been discussed separately.

With respect to moving house, 4 respondents reported that they had been requesting more suitable accommodation for a number of years or months. 2 had been offered different accommodation but had rejected it as it had not fulfilled their expressed requirements. As a consequence they had been told that they had been placed at the bottom of the waiting list.

Another couple were dissatisfied with what had been chosen for them but said they could not refuse it.

2 people said that they wished for advice in chosing their next home so as to keep the provision of adaptations and equipment to a minimum.

2 other people wished to move into residential or sheltered housing but had been told that there is no such accommodation in the West Essex area.

Conversely 4 people stated that they had felt pressurised by professionals to move but had resisted because they did not wish to move away from an area which they knew and were known in and wished to keep the doctor, nurses, home helps etc whom they were already familiar with.

2 people reported that their wish to move had been granted and that they were pleased with the service.

5 respondents stated that though they lived in purpose built accommodation it was not suitable for their needs. Adaptations had still had to be carried out.

Regarding extensions, 5 people stated that they had asked for a downstairs toilet or bedroom extension and had been refused. Conversely, 2 people reported that their extensions had been built eventually but that the design solutions had not been satisfactory.

4 respondents reported that the installation of a hoist, stairlift or a ramp had taken between six months and three years, and 6 remarked that the provision of the adaptation had only partially solved a problem.

3 people reported that there is a slow repair system for malfunctioning equipment.

Of the participants who live in residential accommodation most said that they wished to live in the community. The majority stated that they were unhappy with the organisation of the home and with the attitudes of the staff and said that they did not feel that they could contribute to the running of their home.

3.2 Aids and equipment

Of the 34 people living in the community 23 stated that they had not been provided with aids and equipment for daily living, for example, bathing aids, kitchen aids, feeding aids. A few of those who had received aids said that they had found out about an aid and had asked for it. 6 people had had an item of equipment provided without an assessment and had found it unsuitable and some aids had caused difficulties for other members of the household.

Conversely 6 people stated that they had been recommended a variety of aids and had been given equipment to try.

3.2.1 Communication aids

7 people living in the community had been provided with an intercom which the majority said they found useful but the design and siting was reported to have caused difficulties for others.

5 people living in the community had been provided with an emergency alarm system and all were satisfied with it. However a further 4 people said that they would like to have such a system but did not know about it or had been refused one.

3.2.2 Wheelchairs

11 participants stated that they had not had assessments for their wheelchairs, 3 said that they had had assessments in the past but that their condition had deteriorated and/or their chair required attention or was no longer suitable.

14 participants said that they had visited a wheelchair assessment centre and reported that they were satisfied with the result and that they knew where to contact for further service. A further 11

people who had had assessments reported being dissatisfied. 3 had given details on a form or over the telephone and a wheelchair had been delivered.

3.3 Personal care support

14 of the people living in the community stated that they or their carer carried out all or most of the personal care tasks.

13 reported that they received assistance from a nurse, home help or paid personal care assistant.

3 people said that they had asked for nursing support but had been refused whereas 2 reported that they had had their nursing care gradually increased as their condition had deteriorated.

Some people stated that they did not have to pay for their nursing care whilst others said that they paid partially or totally for theirs.

2 people said they had asked for support whilst their carers were on holiday, 1 had received the service, the other had been refused.

3.4 Domestic support

Of people living in the community 18 reported that they did not receive domestic help. This was satisfactory for the majority, though some said that they would welcome help but did not know where to ask, others said that they could not afford to pay for it and some said their request had been refused.

10 people received domestic support and the majority said that they were satisfied though 4 said that they would appreciate more help or would like the service to be flexible so that they could do their own housework when they feel well enough.

3.5 Health care

3.5.1 General practitioners

The majority reported satisfaction with the service from their GP, however 4 said that no matter what ailed them their GP considered that it was due to their condition.

2 people reported difficulty obtaining their prescriptions.

3.5.2 Hospital experiences

5 people stated that they were unhappy about treatment they had received in hospital and felt that medical staff are not prepared for ill people who have a disability.

3.5.3 Nurses

The majority of people were visited by nurses for dressings and/or to deal with some aspect of their continence. Nurses were reported to carry out a variety of tasks and provide a wide range of information. Most people appeared to be more satisfied with their nurses than with any other service.

3.5.4 Dentists

Nearly half of the participants visited the dental surgery without difficulty, a few saw a dentist whilst in Pine Unit and a few were visited at home by a dentist.

18 people did not visit a dentist either because they had false teeth and thought that visiting the dentist was unnecessary or because they could not get to or get into the surgery and did not know that home visits were a possibility.

3.5.5 Opticians

The majority of people either visited an optician in their local town or at a hospital.

10 people did not visit an optician either because they did not consider that it was necessary or because they could not get to or into the opticians.

3.5.6 Chiropodists

Approximately half of the respondents saw a chiropodist. Of these approximately half paid to be visited at home, though most said that they thought that they should not have to pay, whilst others visited a practice or had the treatment whilst in Pine Unit.

3.5.7 Occupational therapy

The majority of people had been in contact with occupational therapists either for adaptations and aids in the home or for handicrafts elsewhere. A few people reported that they had difficulty in contacting an Occupational Therapist.

2 reported received letters telling them that the occupational therapist had done all that was possible for them and that further visits would not be made.

2 said that they were delighted with the service from their occupational therapist and that they could telephone at any time.

All of those attending the training centre (Treetops) either daily or as residents of Chigwell House omplained about the lack of trained occupational therapists. 1 person had written to Social

Services about the matter and said that a professional had visited but that a further four months had passed and nothing more had been heard.

3.5.8 Physiotherapy

Following housing and transport the majority of people raised the issue of the lack of physiotherapy as causing them most distress.

Of the 48 participants 2 were having physiotherapy at the time of the interview. Most people reported having had treatment in the past but stated that; they had not been given a programme of therapy, they did not know why they had a particular treatment or that the treatment changed each time they saw a different therapist, and that they were called in or treatment stopped with no reason being given.

7 people said that they could not get in for treatment because of lack of transport or the ambulance would not take their wheelchair and 2 felt that they lost the benefit after waiting a long time after treatment for transport home.

A few people said that they had been given exercises to do at home but that there was nowhere suitable to do them and they needed help.

38 people said that they felt that they would benefit from physiotherapy, exercise or massage.

3 people had enquired into or had had private physiotherapy at home but could not afford it on a frequent basis.

2 people said that they were so dissatisfied with the service that they had written to their MP.

Most of those participants who visited Pine Unit for respite care complained that physiotherapy had deteriorated recently and 1 person had written to the Consultant to complain about the service.

Of the participants living at Chigwell House most were upset at the lack of physiotherapy.

3.5.9 Speech therapist

3 people had had speech therapy and all said that they were satisfied with the service though 1 was disappointed that the therapist had left over a year ago and she had not heard from the department subsequently.

4 people stated that they would benefit from speech therapy but either it had not been suggested or had ceased when they had left hospital.

3.5.10 Hairdressing

The majority of participants said that their hair was cut by someone visiting the home or by a member of the family. Some people said that they were able to visit the hairdressers or the barbers. 8 people said that they had to wait until they visited Pine for their hair washing or cutting. Some carers reported difficulty in washing the individual's hair.

3.6 Respite care

19 people had attended Pine Unit, 7 of whom reported that the visits were enjoyable and beneficial, that they were stimulated by occupational and physiotherapy, that it gave their carer a break, that they had made friends and got on well with the staff. However, 12 people stated that they were not happy with various aspects of the Unit, they cited the attitude of the staff, the lack of cleanliness and the lack of stimulation, especially physiotherapy, in recent months. Of these latter most said that they did not wish to go again.

The majority of the respondents stated that the Unit was a good idea but that there should be other opportunities for the carer to take breaks for example for a day or night once a week so that they did not become so tired or ill that respite care was required.

3.7 Transport

Following housing, problems with transport was raised most frequently as preventing them from carrying out activities.

Approximately half of the people living in the community had access to their own or a family vehicle, but most had to rely on there being a driver available and/or had difficulty transferring.

It was reported that there are no accessible buses in the area, only a couple of adapted taxis and no service such as Dial a Ride.

Most people felt that one of these forms of accessible transport would greatly improve their quality of life; they would be able to get to hospital, go to day centres, college, meetings, go shopping or for other days out with their families and visit friends.

3.8 Education

The majority considered that education, whether it be vocational or for pleasure, was out of the question. Their reasons were; because of a combination of; poor eyesight, lack of hand movement or dexterity, frequently feeling very tired and/or ill and lack of accessible transport and toilets.

Those participants who live at Chigwell House reported that they are required to attend the rehabilitation centre (Treetops) for training which most referred to as 'the programme'. Many said they were forced to go but they were bored and that the programme was not tailored to the individual. However, some attended the college in Loughton which most said they enjoyed.

3.9 Employment

The majority of the participants stated that work was out of the question for them due to the same reasons given under education.

Some also thought that if they worked it would affect their financial benefits.

Many said that they were fully occupied doing the few things they could still do but a few said that they missed the social aspect of work.

Some respondents who live at Chigwell House stated that they would like to work but that they did not know what they could do and/or were concerned about losing their benefits or having to pay more to live at Chigwell House. One person had worked and had enjoyed it for a variety of reasons. Two people said that they would like to do voluntary work to obtain experience but did not know how to follow this up.

3.10 Leisure

The majority responded that they were happy watching TV, reading, writing letters, some sewed or knitted, did a little gardening or photography. Many stated that they feel so tired and ill that much of their time is taken in doing the things that they have to do and/or did not feel the need for leisure activities. However, a few said that they were bored or frustrated but that with poor eyesight and impaired hand function they did not know what they could do.

10 respondents stated that would like to go swimming and a few named other activities for exercise, but cited lack of transport and access to facilities as preventing them.

3.11 Social activities

As with leisure activities some people reported that they are content with their social life and do not feel that their disability has changed it, either they still manage to be active, visiting the cinema, theatre, restaurants, being on committees etc. or they had a quiet social life prior to their condition. A few said that they would welcome a more active social life but cited dependency on others and/or lack of transport, and/or lack of accessible toilets as obstacles.

10 respondents were visited by people from Crossroads, this was reported to be appreciated by both the disabled individual and their carer.

3.12 Religious activities

The majority of people, including those living at Chigwell House, stated that either religious activities were not part of their lives, or that they were able to participate in religious activities as they wished to.

3.13 Holidays

12 respondents reported being unable to go on holiday due to them feeling too ill, being in financial difficulty, and/or transport/accommodation etc. being too difficult to arrange due to the severity of their disability.

17 people stated that they take a holiday with their partner, family or friend/s. However transport and lack of accessible accommodation were cited problems.

Few were aware of the information booklets published by RADAR etc. on all aspects of holidays.

A few respondents take holidays separately from their family, these were usually holidays (in this country and abroad) with other disabled people using adapted vehicles and hotels with assistance provided.

Of those people living at Chigwell House the majority take holidays. Most of these stated that they go with a friend or friends from Chigwell House and they all complained that one or more care staff have to accompany them and that they have to pay for the transport, accommodation etc of these staff thus in effect they were paying twice. They all stated that this was next to impossible on the £10 a week which most of them said that they were allowed. Other people go on holiday with organisations or with their families.

3.14 Information

The majority of respondents stated that provision of information, in particular concerning their condition and financial benefits, had been lacking. Only 1 person had heard of a disability information service such as DIAL though on hearing about it, most thought that it would be a useful service and a few said they would like to be involved with it.

Most respondents commented that this study was the first time that anyone had asked them about their situation and how they would like to live their lives. They stated that they would welcome the opportunity to periodically discuss such matters with a professional since it had raised issues they had not know of and given them an opportunity to ask questions and make their feelings known.

3.15 Personal development

Most people said that it would have been helpful to them and their families, including partner, parents and children, if counselling had been available. Many said that their families did not understand their condition, were upset, frustrated, and felt that they had to do a lot of caring but were given little support.

Most participants stated that they were very keen to be involved with professionals to improve the services they and others received, to be involved in a group and to offer support and advice to other people.

Thus recommendations have been made for the formulation and activities of such groups based on the findings of the discussions.

4 Observations

The consultant has made the following observations regarding the responses to the discussions.

4.1 Housing

A consistent theme throughout the findings of the discussions on housing is that of the problem of there being sufficient constructive dialogue between clients and professionals. It seems that many individuals are not always given an opportunity to discuss with professionals the issues that they see as important, that their views are not listened to, or that decisions are made on their behalf. As a consequence unsuitable solutions are offered, and if not accepted they are penalised.

It could be asked, if the statutory authorities do not have suitable accommodation for those who are desperate to move where do they envisage that those who they are encouraging to move should move to?

It appears that the client frequently has to have what the statutory authorities offer under their terms. For example one client asked for a wooden ramp to be told that she could only have a concrete one even though there were structural reasons why a concrete ramp would not be possible and the client felt that a wooden ramp could be used by other clients at a later date, thus she is still without a ramp. However, another client was provided with a wooden ramp without specifically asking for it .

The majority of people complained of having to fight, argue and push for appropriate provisions to be provided, installed and repaired.

It would seem that discussions are not routinely held with clients regarding the possibility of extensions or more suitable adaptations, even when the individuals feel that they are aware of a more appropriate solution.

If appropriate provision had been made it is possible that when the house would eventually becoming vacant it could be earmarked for other disabled people thus keeping costs down in the very long term.

In some cases the users recognised that the proposed solutions would not work or solve their problem. Despite this the adaptations are still carried out or the individual is told to accept the proposed solution or have nothing.

It seems that alternative designs or solutions are rarely discussed with the client. This points to a possible lack of knowledge on the part of individual professionals about the scope of what is available and possible.

Users express concern that money is often wasted whilst their problems remain unsolved.

Also, in some cases professionals seem not to look at the situation as a whole, for example a stairlift is installed without taking into account that the individual may have fits on the stairlift or without addressing the problem of getting into the toilet when upstairs.

In circumstances where provision is made following detailed consultation with the clients they are able to achieve greater independence and therefore make savings for the statutory authorities in subsequent provision of personal and domestic support.

The length of time which some people wait for adaptations such as hoists or stairlifts is a matter of concern. The increase in dependency which this could entail may impose additional costs in the long run in the provision of personal and domestic support.

It also seems that professionals suggest the option of moving into sheltered accommodation to individuals without exploring with them their preference and that some clients are ignorant of the choices.

Another issue is the inconsistencies in the services and advice provided, for example, some people are not enabled to move whilst others in very similar circumstances are; some who do not wish to move are encouraged to do so, and some are denied the house extensions they ask for whilst others have the facility offered or provided.

These inconsistencies do not appear to be dependent upon the area in which the client lives or whether they are living in Local Authority or private housing. Thus it seems that provision is often dependent upon the individual professional the client is dealing with.

The responses given by those who live in purpose built accommodation suggests that the design of such accommodation leaves something to be desired and that future developments should take more account of the individual needs of the clients and their families.

It appears that there is a lack of sheltered accommodation in the area for younger disabled people. This needs to be addressed as a matter of priority.

The people living at Chigwell House appear to have very limited knowledge of what options are available as regards living arrangements. Despite the fact that many have attended special schools and/or training centres (including the training centre at Chigwell House) it seems that they believe that the only alternative to Chigwell House is to live alone in adapted accommodation. There seems to be little knowledge of small group homes.

Also most Chigwell House participants expressed dissatisfaction with the organisation of the establishment and/or the attitude of the staff and being unable to participate in the running of what is their home and own lifestyle. It is a cause for concern that they referred to their rooms as 'the unit', themselves as 'the residents' and to 'being in trouble'. These findings suggest that the opportunities provided at Chigwell House to explain the options of independent living and for personal development are not used effectively.

Thus, there appears to be two main issues. Firstly it appears that professionals do not have an established procedure for discussing with the clients the various options for housing, extensions and adaptations and/or obtain a profile from them of the services they require. Secondly there seems to be no uniform approach for professionals since some clients feel pressurised into accepting inappropriate, simplistic and standardised solutions to their difficulties. These findings need to be addressed.

4.2 Aids and equipment

It appears that clients are not routinely told about the variety of aids and equipment to help them in the activities of daily living. There are a number of publications available which inform people of the range of products available. It is possible that if clients were able to obtain such equipment that they would be less dependent on their carers and feel more satisfied that they were able to bathe and feed themselves independently.

It seems that there are also occasions when a client has been provided with equipment without an assessment. In some cases the individual has then found the equipment to be unsuitable, thus their problem has not been solved, and other members of the household inconvenienced.

This latter point also suggests that follow up visits to clients do not take place to ascertain the suitability of the aids prescribed.

This could point to a lack of knowledge among individual professionals of the range of aids and equipment available and how to choose which are suitable for the client .

However, other participants spoke of having been given information about aids for daily living, of having a variety of equipment to try before making a choice, of having an assessment for equipment and of being followed up to check the suitability of equipment. This could be explained by different procedures in different parts of West Essex except that participants living only a few streets apart gave opposing accounts. Thus it appears that to some extent the provision of aids equipment relies on the personality of a particular professional. Guidelines for the assessment, provision and follow up of equipment could be helpful to the professional and fair for the individual. It could also prove less expensive for the department concerned since studies have shown that a large number of inappropriately prescribed aids are not used and therefore could be benefiting another client.

Regarding the provision of communication aids, it seems that the issue of summoning help in an emergency is rarely raised with the client, even though many participants were concerned about what would happen if they fell, if there was a fire or if there was an intruder. Some have solved or partially solved the problem themselves by purchasing a more suitable telephone. Though, in discussing telephones it became clear that no one was aware that British Telecom (BT) have a whole range of telephones for people with different disabilities. It was also ascertained that some are charged more by BT for hiring telephone adaptations whilst others think that they pay a reduced rate for the rent.

Other participants feel confident about their safety since they have been provided with an emergency alarm system. However, others appear to have been incorrectly advised on their availability or do not know of the existence of such devices. The comments made regarding the latter situation indicates that although clients are concerned about being unable to summon help it has not occurred to them to discuss this with a professional. This may point to a limited knowledge of what the professional can do or lack of opportunity for such discussion.

Regarding the provision of wheelchairs, it appears that only 14 of the 48 participants have been assessed and are satisfied with the service and with their wheelchair.

The main barrier to appropriate provision again seems to be one of information;
knowledge of the assessment centres,
knowledge of how to obtain an appointment,
knowledge of the importance of correct assessment
knowledge of the choice available should they wish to purchase their own,
and
knowledge of the variety of cushions and other accessories which are available.

It seems surprising that when an individual reaches the stage when a wheelchair is required or when a wheelchair user presents to a professional there is no discussion on the above.

It also seems that a follow up visit is rarely made to ensure that the chair is suitable.

However, it does appear that to some extent those who have required a wheelchair more recently have had a little better service

The main conclusion that can be drawn from these observations is lack of effective dialogue between professional and client.

4.3 Personal care support

There appears to be a lack of awareness amongst some clients about what services are available to provide support for personal care, for example, nurses, home helps, paid personal care assistants and voluntary help such as Community Service Volunteers. There also seems to be a lack of knowledge about what funds, such as the Independent Living Fund, are available to pay for a personally tailored package of care. This is often despite clients being in contact with a number of professionals.

There also seems to be inconsistencies in what is provided to clients in similar situations. Some have had intensive and personalized nursing care for years whilst others have been refused assistance and are struggling.

It also seems that the system is inflexible so that carers can not obtain support to cover for a short time while they are ill or on holiday. Flexibility in cover could be less costly to the statutory authorities in the long term since this may reduce the need for a respite care unit.

Often the difficulties of personal care seem to be exacerbated because house extensions or adaptations that people have requested have not been provided.

A number of participants said that this discussion was the first time, in all the years of their disability, that anyone had asked them how they managed with personal care issues.

4.4 Domestic support

There appears to be inconsistencies in that some people wish for or ask for help and are refused, whilst others continue to receive help when they have informed the service providers that it is no longer required. Also some people reported that the hours and tasks were inflexible whilst others reported a much more relaxed approach.

There also appear to be anomalies in payment for the service with some people saying that they could not afford the support they felt they needed. It is possible that if people knew about the Independent Living Fund they could pay for their own domestic support and tailor it to their needs. For example in the case of the young couple who sometimes both feel so ill that they eat cereal for every meal, using the Independent Living Fund they could pay someone to prepare them a meal.

Improved information provision and dialogue with professionals could enable people to achieve more appropriate solutions to their domestic support requirements.

4.5 Health care

It appears that there is generally a lack of information given to clients by professionals. For example, that GP's and hospital medical staff do not provide information about an individual's diagnosis and prognosis, about treatment or where to contact for further information. There also seems to be information lacking about the home visiting services of dentists and opticians or information about accessible opticians and dental surgeries.

There seems to be lack of discussion between professionals and clients regarding the treatment being given, for example in physiotherapy, the reasons for the treatment and the reasons why treatment is sometimes on an irregular basis. From the responses of the clients it appears that they would very much like to be involved in the long planning of treatment

The responses of the users also indicates that there are inconsistencies in the services provided, for example, one person had had nursing care gradually increased as her disability had deteriorated, yet another woman in a seemingly deserving situation had been denied nursing care. Another example of inconsistency is that some people were in contact with a named Occupational Therapist who would visit them for discussions and bring them equipment to try, whereas others said that they found it difficult to contact a therapist or had received a letter from a therapist saying that no further contact would be made.

It also appears that some professionals do not take account of the particular needs of their disabled clients when giving advice, eg hospital medical staff, physiotherapists, continence advisers.

There also seems to be deteriorations of some services which clients once considered to be satisfactory. For example, some said that they had had good contact with occupational therapists but that this had deteriorated or ceased due to staff leaving or reorganisation. Others reported that physiotherapy in Pine Unit was not so frequent as it had been in the past.

The following issues were raised;
access to buildings, eg the hospitals, GP surgeries, opticians, dentists ect.,
being unable to attend for treatment meant because of;
lack of transport ,
because ambulances would not take wheelchairs,
because transport was late,
the long wait after treatment to return home.

Regarding the people who live at Chigwell House there is cause for concern that the training centre does not have a qualified occupational therapist on its staff. This seems to be imperative for the assessment of the individuals, for the knowledge of aids and equipment and for the training and use of such equipment and Activities for Daily Living (ADL) skills. Possibly tied in with this, is the fact that despite the 'programme' there seems to be a lack of knowledge and understanding amongst the residents about visiting dentists and opticians etc. Since there is such feeling amongst the residents about the lack of a qualified occupational therapist at the centre this should be addressed as a matter of priority.

4.6 Respite Care

Though some clients consider that the respite care unit offers an important service, in that it enables their carer to have a break and it gives them an opportunity to socialise and to have treatment such as physiotherapy, it seems that the service offered should be reviewed. For example, some clients complained about the attitude of some staff and the lack of care such as being turned during the night or help to go to the toilet. Thus staff training may be required. The deterioration in the physiotherapy service also needs to be addressed. It would seem that attendance at Pine would be a good opportunity for people to receive information and advice about their disability and to take part in stimulating activities. At present this does not seem to occur.

There do not appear to be any other services which clients and carers can use to prevent a crisis occurring which requires long stays away from home, which some people found distressing. Considerations should be given to the provision of services such as; night sitters, more volunteer visitor and day centres etc. so that carers can have shorter and more frequent breaks.

There may also be other strategies which clients could be informed about which would prevent the need for respite care, such as the possibility of using the Independent Living Fund (ILF)to employ someone to do more of the caring to release the partner. However, few participants were aware of the ILF.

4.7 Transport

There appears to be a lack of information for people about the advice available or choice of cars and aids and adaptations. There also seems to be confusion about mobility allowance and Motability.

Those who are unable to drive or who are unable to use a car seem to be without any other transport options since there appears to be no adapted buses and no service such as Dial a Ride in West Essex. Since this limits people's ability to attend for treatment or have a social life, etc. this needs to be addressed as a matter of urgency.

Though there seem to be a few adapted taxis in the area there do not appear to be enough to cope with the demand. Though at the same time publicity should be improved since there is a lack of knowledge about their availability.

4.8 Education

Though most people living in the community did not see education as a priority some people said that they would like to maintain existing skills or learn new ones. There were also a number of people who said that they would like to be able to leave the home more frequently for stimulating activities. It would seem, then, that a useful service would be the provision of day centres for younger disabled people where a variety of skills could be maintained or learned. It is also possible that bathing, physiotherapy and information and advice about disability issues could be provided at such centres. This would also provide the break that carers were asking for. It is recognises that a number of centres would be required throughout West Essex, close to people's homes and transport made available.

Since there seems to be dissatisfaction in the design and to some extent the content of the 'programme' at Chigwell House it is suggested that this is reviewed to provide the service which the users require. Also all residents need to be made aware of the possibilities for education and training at establishments outside Chigwell.

4.9 Employment

The majority of people living in the community did not see employment as an issue due to the severity of their disability. However, this was a lack of knowledge about Disablement Resettlement officers, sheltered workshops, Remploy etc. so that had people wished to work they did not know of the services available to them.

This also seemed to be true for people living a Chigwell House. Despite 'the programme' and the fact that many had attended special schools and/or seen a Disablement Resettlement Officer most had never had anyone discuss the possibility of work with them. One said that once he left Chigwell House he would not be able to sign on for benefits or go for interviews because of the lack of transport. Two people said that they would like to work on a voluntary basis to obtain experience but did not know how to follow this up. There appeared to be no knowledge of other training programmes, sheltered workshops or Remploy, etc.

4.10 Leisure

Since the main issue raised by people living both in the community and at Chigwell House was swimming it seems that there is a need to ascertain which pools are accessible. The possibility of sessions for people with disabilities could be be looked into for those who feel less confident about mixed swimming. Otherwise more widely available information about accessible pools would be helpful.

As for other leisure activities most people seem content to arrange for their own interests though the availability of day centres may introduce people to activities which they had not previously thought of.

4.11 Social activities

As with leisure activities the majority of people living in the community and at Chigwell House were content with their social life. However, improved access to buildings, more accessible toilets and suitable transport would enable more people to achieve a more active social life.

A number of people already attend day centres but some find them unsuitable because of the predominance of older people and/or the lack of stimulating activities. This would point to the need for day centres geared for younger disabled people offering a variety of services.

The Crossroads scheme seems to do an important job in freeing the carer for other tasks or for a rest and in bringing a 'breath of fresh air' for the client. However, more volunteers would seem to be needed so that more people can receive the service.

4.12 Religious activities

Religious activities do not seem to be an issue, most people seem to be able to make their own arrangements.

4.13 Holidays

There seems to be a need for information on accessible accommodation both not catering exclusively for and catering exclusively for disabled people and organisations which arrange holidays for disabled people to be disseminated.

4.14 Information

The theme running through all the responses to all the topic areas is that of lack of information. People do not know that there is an answer to their question or a solution to their problem, neither do they know where to go for information or who to ask. Often in attempting to find out they are passed from department to department. Thus trying to obtain information is further hampered by a lack of constructive dialogue between professionals and clients.

Some people are confused and anxious about their disability, prognosis and treatments etc. which is compounded by concern about their financial situation. This latter could be relieved by adequate information about benefits.

It would seem that there is a need for a specific information provider. For example, in the early days of a diagnosis a client could be contacted by a professional who could have the role of listener and information provider and who could put the client in touch with the most appropriate professional or department. This named individual could be the first point of contact for any enquires the client has thus this individual could filter enquiries and perhaps prevent other professionals from becoming over loaded.

This need not necessarily open the flood gate for requests and demands or be in conflict with the principles of 'care in the community' where people are encouraged to be self supporting. From the discussions it seems that most people are very conscious of the expense of the services they receive and are concerned about wastage. They also appear to have many needs which could be answered by providing information. Once they have an answer to their question or understand a situation it may be that they are able to find ways of meeting that need on their own or by some other means. For example, the majority of people did not know about the Independent Living Fund, when it was explained to them many could immediately see where they could have used the fund to employ someone to do the particular task/s they required when they required it. Thus it could have freed the services from an expense and a professional from a task.

Despite 'the programme' the people living at Chigwell House seem to lack basic knowledge about where to obtain information about benefits and support groups etc. this situation needs to be addressed.

4.15 Personal development

The is a need to provide individual and family counselling.

5 Recommendations for implementation of the findings of the Living Options Enquiry

General recommendations

I A consistent theme running thorough the findings of the enquiry is the problem of constructive dialogue between the professionals and their clients. Though the majority of participants said that they would like to work with professionals to plan their service needs they did not have any suggestions about how this could be achieved other than talking to professions, which some felt they had tried without success. Thus, there is a need to improve communication channels between professionals and clients.

Thus, procedures should be set up and guidelines produced to help professionals in listening to, providing information to and explaining to clients.

II As well as dialogue being improved between a professional and a client, communication could be opened up between client and client to offer support and advice, this happens to some extent in groups such as the Multiple Sclerosis Group but could be extended. The clients themselves could also form groups to advise and support professionals.

Thus the consultant suggests that a network of interested disabled people be set up in the West Essex area, that the issues raised in this study be put to the groups and that they are provided with help, support, encouragement and advice to enable them to take up the issues raised in a way they feel to be appropriate. Initially suitable meeting places will need to be identified and transport arrangements made whilst others may wish to contribute from home, or to meet in each others homes. Support may be given in the form of for example, personal development and assertiveness training as requested. As the group becomes more established and confident it is envisaged that outside support could be gradually withdrawn.

It is suggested that the main areas for the groups could be, around Loughton, around Epping, around Harlow and around Bishops Stortford, and that the groups could, initially, concentrate their efforts on the three most frequently raise issues.

The 47 people who have already participated, and who are still in the area, could be contacted to ascertain if they would be interested in being involved in the actions suggested by joining a group who meet outside the home, or meeting in each others homes, or being involved from their own homes.

Other disabled people in the areas could be contacted to ascertain whether they would be interested in joining such a network for action.

Disability groups in the areas could be contacted to ascertain whether groups or individuals would be interested in participating.

5.1 Housing

So that a higher degree of independence can be gained in their home the groups should work with the relevant departments to:

set up a register of existing housing (private, local authority and Housing Association) suitable for disabled people (RADAR have recently produced a report which would help with this),

ascertain if it is possible to encourage all builders of new housing, whether they be private, local authority or Housing Association, to build 'lifetime homes',

to produce or acquire design guidance for accessible homes to assist in the above,

look into the possibility of providing sheltered accommodation for young disabled people.

investigate the costs of adaptations and extensions so that decisions can be taken with the support of knowledge.

5.2.1 Communication aids

The emergency alarm centres should be assessed to ascertain whether more people and younger people with disabilities could be included on the network. If not it should be ascertained if the service could be extended or if additional services could be set up and it should be publicised to alert people to its existence.

5.2.2 Wheelchairs

The issues raised in the survey regarding wheelchairs could be discussed with the local wheelchair assessment centres to determine whether a strategy can be worked out for calling in those who have never been assessed and for standardising the procedures for attending the centre. Information should be produced to enable clients to understand their provision.

5.5.4 Dentists

A guide of accessible dentists could be produced highlighting those who will undertake a home visit.

5.5.6 Opticians

A guide of accessible opticians could be produced highlighting those who will undertake a home visit.

5.5.7 Occupational Therapy

Health and Social Services occupational therapists should give consideration to producing a checklist of the services and equipment that clients are entitled to in order to ensure that all clients receive the same service.

It is strongly recommended that a suitably qualified and experienced occupational therapist is appointed at Chigwell House training centre.

5.5.8 Physiotherapy

To provide a feeling of physical and mental well being the groups should:

ascertain whether there is a physiotherapist with knowledge of neurophysiotherapy to treat their specific needs and if not to encourage the appointment of a suitable person,

work with physiotherapy departments to encourage the development of long term treatment plans and for adequate advice and information about their treatment,

look into the possibility of a 'flying physio' to visit them in their homes and/or to ascertain whether small groups of people could have treatment in schools, surgeries or day centres near their homes,

ascertain whether a qualified physiotherapist is vital for carrying out such treatment or whether a P.E. or other fitness instructor could carry out such exercises as are necessary either without further training or after instruction,

look into the possibility of using local swimming pools,

5.6 Respite care

Hold discussions with the staff at Pine Unit about the issues clients voiced dissatisfied with.

Investigate the provision of physiotherapy in Pine Unit.

Investigate the provision of more flexible respite care to prevent people reaching a crisis, eg night sitters, volunteer and paid visitors, day centres, cover for carers at times of illness or holiday.

5.7 Transport

To enable users to attend for treatment and to carry out social activities etc. the groups should work with the relevant departments to:

investigate the provision of at least one adapted bus and suitable routes,

ascertain how many adapted taxis are available in the area, how many are needed and provide publicity about them,

work with the relevant authorities and the taxi drivers to improve the service,

investigate the findings of the Dial a Ride survey and ascertain if it is or is not to be implemented and if not whether any steps can be taken to reverse this,

look into the possibility of using volunteer drivers for some services,

obtain and disseminate information on private vehicles and aids and adaptations amongst disabled people.

5.8 Education

Investigate using local colleges, schools, day centres and other places as meeting places where education and training could be carried out.

Contact experts on ideas for stimulation and therapy.

5.9 Employment

Investigate the possibility of sheltered workshops, Remploy, working from home, retraining, etc.

Liaise with the local DRO's.

5.10 Leisure

Investigate swimming and other facilities in the area for people with disabilities.

5.11 Social activities

Investigate the possibility of providing day centres where clients could obtain information, lunch, bathing, see aids and equipment, have physiotherapy and/or exercise, learn new hobbies, etc.

5.14 Information

Investigate the feasibility of restarting DIAL.

Leaflets which give basic information about a variety of disabilities and/or where to go for more help could be produced and distributed among disabled people, GP's and other paramedical staff for them to give to clients.

Give serious consideration to the creation of a post for an information provider. This named individual should be the first point of contact for any enquires the client has thus this individual could filter enquiries and provide information.

5.15 Personal development

Investigate the possibility of providing counselling, awareness training, assertiveness training, etc.

Chigwell house

A thorough assessment of the aims of Chigwell House and the training centre should be conducted to establish with the residents how best these can be carried out so that those who live there are more involved and satisfied. It is considered that an external facilitator should be engaged to work with the clients at Chigwell House to enable them to work towards bringing about the change they desire.

6 Findings of the enquiry

This section pulls together the responses of the participants under the various subject headings and discuses the findings. The findings in each section are followed by the observations of the consultant. The numbers in brackets refer to quotes from the individuals to illustrate the points made, these are to be found in the Appendix page 46.

6.1 Housing

The main issues raised when discussing housing were;
wishing to move house,
wishing to remain in their own homes,
wanting information on the choice of a new home,
the inadequacies of purpose built accommodation,
wanting an extension
and
he provision of adaptations.

6.1.1 Moving house

1 couple who were leaving Chigwell House and 2 people living in the community reported that they were desperate to move to more suitable accommodation (1, 2, 59, 60) which they cited as being;

accessible,
having doors through which and space in which to manoeuvre their wheelchairs,
accessible toilets and bathrooms
and
space to store the the aids and equipment which they had as a consequence of their disability.

They also said that it was important to them to be close to shops and family and to be able to keep the doctor, nurses, home helps, etc., whom they were already familiar with. The respondents said that they had tried to discuss these requirements with the professionals but had still been offered accommodation which did not fulfil their requirements and which they thought was unsuitable. 1 couple said that they had refused such accommodation and had been told that they had been moved to the bottom of the waiting list despite already waiting for two years (1), whilst another couple said that they had been told that if they did not accept the accommodation offered they would have to return to the unit at Chigwell House (59, 60).

2 people living in their own property reported that they wished to move into more suitable accommodation, either into other private property or Local Authority housing, and had asked for advice (on design, financial aid etc) because they were concerned that they may not make a sensible

choice thus costing the services more money in the provision of adaptations and in the new premises (3, 4). However, they stated that advice had been refused with the result that 1 said that she spent most of her time in her bedroom awaiting the provision of a mobile hoist had the other has now moved out of the area.

Conversely 5 people stated that professionals had suggested that they move house and 2 people had been enabled to move.

Of the former, 4 had not moved citing as reasons;

that they had helpful family or neighbours in the area,
that they had brought up a family in the house
and
that the suggested property had not been close to shops (5 - 8).

1 respondent said that she had taken the advice to move and regretted it (9) because the new home was in an unsuitable location and she did not know anyone. She also said she was concerned that it had been a costly exercise for the Authorities since she considered that inappropriate adaptations had been carried out in both dwellings.

2 respondents had chosen to move as a result of their disabilities, 1 couple said that they would have welcomed more help and advice (10) and the other couple stated that they had not received any advice (11).

2 participants, stated that they wished to move into residential accommodation or sheltered housing (14, 15) and a third respondent said that his wish was to move house but to remain with his family, but the professionals had suggested that he moved to sheltered accommodation (16). However, 2 said that they had been told that there is no such accommodation in West Essex (15, 16) and a third stated that he did not know what possibilities existed (14).

5 people stated that they live in purpose built accommodation. However, one respondent said that though a property had been built for him he had not been allowed to be involved in the design and that mistakes had been made though these had been eventually rectified which had added stress to him and his family and the cost to the council had concerned him (17). Another couple reported that expensive modifications had been required which had taken 15 months and that they had been virtually imprisoned during that time (18) and a further respondent said that the only difference was wider doors (19).

5.1.2 Extensions

5 people wanted downstairs extensions, for example, a downstairs toilet and/or bedroom, but they all stated that they had been refused even when there were no other means of getting upstairs to the toilet or to bed or a stairlift was inappropriate (6, 9, 21, 35). Conversely 1 couple said that they

had been offered an extension, which they understood would be paid for by Social Services, but they recognised that the design of their house was unsuitable for an extension and so are organising their own move (25).

2 people stated that they had got extensions eventually but that they were not satisfied, 1 said that the building work was poor and that the design was inappropriate so that the problems had not been solved (23). Both respondents reported that the building work took a long time (24).

5.1.3 Adaptations

Due to the severity of their conditions most people had been provided with one or more adaptations such as a ramp, stairlift, hoist, or alterations, with varying success.

Respondents reported that;

they had been brought inappropriate equipment (26, 31),
that they thought that inappropriate adaptations had been suggested or carried out (13, 21, 32, 35)
that they were concerned that Social Services money was being wasted (2, 9, 17, 26, 30),
that they had had to wait between six months and three years for adaptations (27, 36, 37)
and
that the alterations or adaptations they had requested had not been carried out or provided (30, 33, 35).

A number of respondents stated that they had had difficulty discussing their needs with or convincing the Authorities of their request and/or that they had been made to feel guilty about the cost (26, 29, 32, 33, 34, 38).

Conversely other respondents reported being satisfied with the Authorities and adaptations that had been provided (39 - 45).

A number of people reported that the service for the repair of stair lifts, hoists etc. was slow (32, 34, 38).

5.1.4 Chigwell House

The participants who lived in residential accommodation, Chigwell House, were asked;

if it had been their choice to move to live there,
whether it had been discussed with them,
whether they could decorate and furnish their room as they wished,
whether they liked living there,
whether anyone had ever asked them where they would like to live
and
whether they would like to live elsewhere and if so in what kind of arrangement.

Of the 14 participants;

7 stated that moving there had been discussed with them and that it had been their choice (48, 49, 50, 51, 54, 55, 57),
5 said that they had not had a choice (52, 56, 58, 59, 60)
and
2 said that they did not know or could not remember (47, 53).

They all stated that they were either able to decorate their rooms or put up posters and have their own furniture.

3 said that they were happy living there (48, 54, 56)
5 said that they were not happy (47, 57, 58, 59, 60)
and
6 said that they were unhappy sometimes (49, 50, 51, 52, 53, 55).

They reported that they were;

unhappy with the attitudes of the staff (47, 52, 53, 58, 59, 60),
the rules (51, 58)
and
with the periodical review (48, 51, 60).
4 (51, 52, 56, 57) said that it had been discussed with them where they would like to live
10 said that it had not been discussed with them (47, 48, 49, 50, 53, 54, 55, 58, 59, 60).
1 said that she did not wish to live elsewhere (56),

3 said that they did not know if they wished to or had not thought about living elsewhere (48,53, 57)

3 were to move shortly, though 1 did not know this and 2 stated that they were not happy with the arrangements (47, 59, 60),
1 was returning to his own home (51)
and

the remainder said that they would like to live in sheltered accommodation, or with a few other people (49, 50, 52, 54, 55, 58).

6.2 Aids and equipment

The 34 participants living the community were asked about the quality of information or advice they had received about aids and equipment, for example, bathing aids, food preparation aids and feeding aids. 23 people responded that they had not been told about such equipment and that they did not know about such equipment (for example, 61, 62).

They were also asked whether they had been provided with such aids and if so what had their experience been.

1 woman responded that no one had told her about kitchen devices but that they would have been useful. 1 person said that she had seen a bath lift advertised in a magazine and had asked for one. It had been provided but without assessment (63). 2 people said that they had been given bath lifts but that their partners could no longer use the bath (eg, 64). Another person said that she asked for help with her kettle and was given a kettle stand, 'but it wasn't any good, it was just as dangerous, I scalded myself'. 3 people said that they experienced difficulty with eating. 1 person said that she had been given cutlery, 'but I don't find it an advantage'. 1 person said that she had been given, 'a knife with a BMX handlebar handle, but they didn't have a fork so they told me to get one of these types of handles and put it on a fork. We thought for ages what it was and where to get it from, then we realised it was from a bike handlebar and tried the bike shops, but it doesn't fit very well'. A third person said that he had been given cutlery but that it was not suitable for him.

Conversely 6 people reported that they had been told about a variety of aids and some people had been brought equipment to try (65 - 70).

6.2.1 Communication aids

7 people said that an intercom had been fitted at the main door and another respondent thought that one would be useful. However, they had not all been successful, 1 lady had difficulty with the design of the aid and another said that it had been fixed in an inappropriate position (71, 72).

2 people had bought a hands free telephone.

7 people had bought a cordless telephone which they carried about with them, however one respondent said that she did not think she could use it if she fell.

5 people had an emergency alarm system which is initiated by pressing a button on the telephone or a pendant worn around the neck. A person at a centre calls back and if no response is received predetermined numbers are phoned and someone with a key makes a check on the individual.

4 people stated that they would like such a system but had not heard about them before (eg, 73, 74) and 1 person said that he had been told that he was too young to have one (75).

2 people said that they used a conventional baby alarm to call a carer from another part of the house.

1 woman used a wire free door bell to summon her carer.

2 people had a Possum system for the door, radio, television, lights etc.

6.2.2 Wheelchairs

11 of the 48 participants reported that they had not had assessments for their wheelchairs, some of whom had been using the chair for up to twenty years (76 - 86).

4 people bought their own chairs and did not receive any advice (87 - 90).

3 people said that they had had assessments in the past but the chair was now old or their requirements had changed and they did not know how to obtain a re-assessment or could not contact someone about it (91 - 93).

14 people said that they had been assessed for their wheelchairs and were satisfied with them (94 - 107). A further 11 people who had been assessed reported that they were not satisfied either with the service and/or their wheelchairs. Comments included;

having to wait a long time for the chair,
the chairs being too wide to go through the doors at home,
wanting an electric chair,
having difficulty propelling themselves,
not being given information about wheelchairs,
chairs being too heavy to push or lift into a car,
and
wishing to buy their own but finding them too expensive (108 - 117).

2 people said that they had given measurements on a form (106, 118) and 1 over the telephone (88).

7 people stated that they were uncomfortable in their chairs and a couple said that as a consequence they had developed pressure sores. 7 said that they required a more comfortable cushion but did not know where to obtain one from (77, 82, 86, 109, 114, 116, 119).

6.3 Personal care support

This section does not include a discussion of those who live at Chigwell House since personal care support is provided when necessary by staff and seemed to be an issue only to those who were moving.

The family carers (husband, wife, partner, parent or brother) reported that they did all or most of the personal care tasks (helping at the toilet, changing pads, helping with a catheter, bathing, hairwashing, teeth brushing, dressing, turning in the night, etc) for 12 of the participants (120 - 131). Most were satisfied with this arrangement.

However;

5 people stated that they would appreciate support from a nurse,
1 reported that she wanted help for her husband whilst she took a holiday (123),
2 men said that they asked for help because of their own ill health (124, 127),

1 woman stated that she wanted help to bath her husband because he could not get upstairs to the bathroom and was concerned that he only had a bath when he went into Pine (129),

1 man stated that he requires 100% care and had had no input from the Social or health services but when he asked for personal care support he said that he felt that they 'shrugged their shoulders of me'(143).

All said that their request had been refused.

13 people reported that they have support from a nurse, home help or paid personal care assistant (132 - 144).

5 people said that they paid wholly or partially for this support from their allowances or the Independent Living Fund (132, 138, 139, 146, 144).

2 men said that they received help with bathing their wives because they had been told that they were not allowed to bath them (135, 137).

1 woman said that she had had to fight for a nurse to help her mother to bath her despite her mother having had a hernia (142).

Another woman said that her GP had organised a nurse for her and that her nursing care had gradually been increased as her condition had deteriorated (136).

5 people said that they manage their personal care alone or by using aids and equipment.

6.4 Domestic support

Those living at Chigwell House have not been included in this section since they did not appear to see it as an issue. Some or all of their meals and cleaning is provided by the staff. Some people make their own breakfast and/or tea and wash up after themselves after some or all meals. Most keep their own roms basically clean and tidy and do their own laundry depending upon their ability. In the training flats all domestic tasks are carried out by themselves. The three people who took part in the study who were living in the training flats did not raise any issues in this area.

Of the 34 people living in the community 18 reported that they received no domestic help. Of those 18 the majority of the carers were female. Most people stated that this was satisfactory and some said that they would decline the offer if it was made.

4 people reported that they wanted help. The reasons that they gave were;

because their carer was elderly (145),
convalescing (146)
had osteoarthritis (147)
or a bad back (148).

They stated that help had been withdrawn, refused or that they could not afford to pay for it.

10 people stated that they receive domestic support.

Of these 3 said that they were delighted with the support they received, that their home helps were flexible in hours and duties and were like friends (157, 160, 161).

4 said that they feel they would like more hours and more or different jobs doing (152, 154, 156, 159).

7 people did not mention paying for the service (154 - 161).

1 said that she paid something towards the service and could not afford to pay for more time (152).
1 who had had the service said she had paid for it and could not afford it (146)
and

1 who had requested the service said that he had been told that he would have to pay for it and that he couldn't afford it (157).

6.5 Health care

6.5.1 General Practitioners

5 people said that they went to the surgery, though 2 (163, 164) commented that it was not accessible. The remainder were visited at home or at Chigwell House.

The majority said that their GP had not given them any explanation of their disability, the possible causes, effects or long term prognosis or any information or contacts about where to find out about the condition, health or social service support (eg. 473 - 481).

Most respondents stated that they were rarely ill despite their disability and that if they were ill it was unrelated to their disability, eg a cold, and some were not taking medication.

4 said that they were particularly satisfied with the treatment from their GP (165 - 168), their reasons were that the GP gave them advice and was supportive.

9 people reported being dissatisfied with their GPs (169 - 177), their reasons were;

that no matter what ailed them their GP said that it was due to their disability (171, 172, 175, 176),
that their GP did not visit them to check that they were alright (eg. 170),

that their GP spoke to their carer and not to them,

that the GP did not give them information and advice (eg. 173, 177).

Some people experienced difficulty obtaining their prescriptions (eg. 178).

6.5.2 Hospital experiences

6 people commented negatively on the care they had received from a hospital (180 - 185). They reported that;
they did not feel that they had been attended to adequately,
that they had been expected to return daily for treatment when they did not have transport,
that they had been made to 'feel a fraud',
that staff had made them feel guilty,
that staff had been rude,
and
that when they had asked for information about self care it had not been provided.

6.5.3 Nurses

The majority of participants living in the community were visited by a nurse for bathing, dressing and changing medical dressings etc. Many people spoke highly of their nurses and reported that they provided them with information and advice.

However,

3 people stated dissatisfaction with the service (192 - 194),

1 said that he had asked for a nurse to care for his wife so that he could work and had been refused (192),
1 had been told that the nurse was too busy to visit her (193)
and
1 could not understand their rules about giving him injections (194).

7 people reported that they were not visited by a nurse. 2 thought that if they required a nurse that they would be able to telephone the surgery be visited by one.

9 (2 people at Chigwell House) people said that they had a nurse to deal with some aspect of their continence.

6 of those living in the community reported that they were not satisfied with the service (186, 187, 189 - 191, 193), their reasons that they gave were;
the exercises were difficult to do in a wheelchair,
the reason for the catheter was not explained,
the products were expensive,

that the continence nurse was difficult to get hold of
and
that the nurses complained about them.

6.5.4 Dentists

20 participants reported that they were able to visit the dentist in their wheelchairs, though some people living at Chigwell House said that transport was a problem.

4 people were visited at home by the dentist (one of whom lived at Chigwell House).

18 people stated that they did not visit a dentist, some because they had false teeth and said they thought it was no longer necessary, others because transport was a problem and/or because they did not know of an accessible dentists surgery (eg. 196 - 198).

Some participants living at Chigwell House said that no one had mentioned them going to the dentist.

4 people saw the dentist whilst staying at Pine Unit.

6.5.5 Opticians

12 participants reported that they visited an optician in their town.

4 people stated that they visit an optician at a hospital or at Moorfields.

The remainder reported that they did not visit the opticians (eg. 199 - 204), the reasons that they gave were; that they did not have transport and they had been told that there was nothing anyone could do for their vision.

Of those living at Chigwell house;
3 people stated that they go to town but that transport was a problem,
3 said they were visited by an optician
and

6 reported that they do not see an optician and 2 wanted to but had had difficulties going about it (205, 206).

6.5.6 Chiropodists

9 people reported that they, their carer or staff carry out their foot care.

9 people said that they arranged for a private chiropodist to visit them at home. Most of these commented that they found the service expensive, did not feel that they should have to pay and would have had more treatment if they had not had to pay.

2 people reported that they visited a practice in town and 1 thought that chiropody would be useful.

6 people said that they saw a chiropodist whilst in Pine Unit.

4 participants who live at Chigwell House reported that they were visited there but that they found the service expensive at £13 a visit.

6.5.7 Occupational Therapy

The majority of participants stated that they had seen an Occupational Therapist for aids and adaptations in the home or handicrafts elsewhere.

All but one of the respondents who had done handicrafts stated that 'it was a waste of time'.

When asked whether they had received advice about Activates of Daily Living (advice on techniques for dressing, food preparation, feeding, bathing, etc.) from an Occupational Therapist all responded that they had not and that they did not know that this was a service that therapists could provide.

5 people said that they were or had been pleased with the service from their occupational therapist (212 - 216), that they had been given equipment and information about aids and financial benefits.

2 people reported that they could telephone their therapist who would then visit to discuss their needs. 2 users said that they had been able to do this in the past but that due to reorganisation they could no longer do this.

Some participants stated that they had had to give their occupational therapist (OT) details of the aid they wanted because the OT had not understood what they were asking for (eg. 217).

A few people reported that that their occupational therapist had contacted them to say that she had done all that was possible for them and would no longer be contacting them (eg. 218, 219).

All of those attending the training centre (Treetops) either as day visitors or as residents of Chigwell House complained about the lack of trained Occupational Therapists (eg. 220 - 228). They remarked about the lack of assessment for for aids and equipment and the teaching of skills such as dressing. Many stated that although they liked the trainers and that the trainers did the best that they could they needed occupational therapists who were trained to give expert advice, information and assessments.

1 person reported that he was attending St Margaret's hospital for Occupational Therapy and that he was pleased with the service (228).

One person reported that he had written to Croft House in October 1991 to as for Occupational Therapy at Treetops, that a professional had visited in the December but that by mid-February he had not received a reply as to what was happening (222).

6.5.8 Physiotherapy

Following housing and transport, lack physiotherapy was the topic which most people raised as casing them distress.

Of the 48 participants 2 said that they were having physiotherapy at the time of the interview.

Most people reported that they had had treatment in the past and commented that;

they felt better physically and mentally for it,
being in a wheelchair they felt that they would benefit from some kind of exercise,
they had aches and pains which they felt would benefit from exercise or massage,
they would like the opportunity to stand up (eg. 242, 251, 270, 272).

However, 7 stated that;

they had not been given a programme of therapy,
they did not know why they had a particular treatment,
the treatment changed each time they saw a different therapist,
and
that they were called in or treatment stopped with no reason being given (230, 235, 244, 245, 247, 253, 256).

7 respondents said that they could not get to hospital for treatment because of lack of transport or the ambulance would not take their wheelchair (230, 235, 242, 243, 249, 250, 256) and 2 stated that they lost the benefit after waiting a long time after treatment for transport home (240, 246).

A few people said that they had been given exercises to do at home but that there was nowhere suitable to do them and that they needed help (244, 247, 251, 255, 256).

38 people said that they felt that they would benefit from physiotherapy, exercise or massage (eg, 229, 232, 235, 238, 239, 241, 242, 246, 247, 249, 251 - 257).

3 people had enquired into or had had private physiotherapy at home but could not afford it on a frequent basis (235, 242, 253).

2 people said that they were so dissatisfied with the service that they had written to their MP (242, 243).

Most of those participants who visit Pine for respite care complained that physiotherapy had deteriorated recently (259 -266) they commented that;

there was no porter to take them,
the physiotherapist was too busy,

they were too old or that nothing more could be done for them or that the physiotherapist was not understanding about their condition.

1 person said that she was so dissatisfied with the service at Pine that she had written to the Consultant to complain along with other patients.

Of the participants living at Chigwell House most were upset at the lack of physiotherapy.

8 people said they wanted physiotherapy (eg. 268 - 272) qualifying it by saying it would make them feel more comfortable.
2 said they did not know if it would do any good
4 did not think they needed it.
2 said they tried to do exercises themselves.

6.5.9 Speech therapy

3 people stated that they have had speech therapy. They all said that it had been offered and not asked for. They were all pleased with the service and had been given advice on drinking, straws, diet and Possum etc (276, 277). However, 1 lady was disappointed that her therapist had left in December 1990 and that she had not heard from the department since (273).

1 woman who had had a stroke was difficult to understand but said that had not had speech therapy since leaving hospital (275). 3 people who were unintelligible said that they had not had speech therapy, one communicated by writing, the others are understood by their wives (274, 278).

No one at Chigwell House thought that they required speech therapy.

6.5.10 Hairdressing

The majority of participants said that their hair was cut by someone visiting the home or by a member of the family. Some people said that they were able to visit the hairdressers or the barbers. 8 people said that they had to wait until they visited Pine for their hair washing or cutting. Some carers reported difficulty in washing the individual's hair.

6.6 Respite Care

19 participants had attended the Pine respite care unit. 7 people reported that they had found the stay enjoyable and beneficial (279 - 285). They said that;

they knew when the stay would take place so that they and their families could plan ahead, they were stimulated with occupational and physiotherapy and felt that it gave their carer a break, they had made friends there and had a good relationship with the staff.

However, 12 people reported that they were not happy with various aspects of Pine Unit (286 - 297). They and/or their carers gave as reasons that; they do not like to be away from home, they do not have physiotherapy, the food is cold, the toilets are dirty, there aren't enough blankets, the staff don't turn them at night, it is difficult for their carer to visit, they don't like the attitude of the staff.

Of these 12 the majority stated that they did not wish to visit Pine Unit again.

In discussing the issue of respite care none of the participants said that they knew of any alternative to Pine. Most said that the idea of respite care was good but that it came too late, that they had to have a crisis or be at breaking point before they or their partner could have the service. Many said that they wished there was a service to give their carers a frequent break so that they would not reach the stage of requiring respite care. The suggestions they made were; someone to look after them or somewhere for them to go during the day so that their carer could work or do other tasks, or someone to be there at night to turn them so that at least their carer could have a good night's sleep.

6.7 Transport

Following housing transport problems were raised most frequently by the respondents. When discussing other topics such as attending for medical treatment, education, employment, leisure, social activities and holidays lack of suitable transport was cited as preventing them from carrying out activities.

6.7.1 Car

25 participants living in the community reported that they either had their own car or used the family car, 1 woman had a 'scooter'. 2 people stated that they had purchased vehicles into the back of which they drive their wheelchairs, but that they were reliant on other people to drive them.

A number of people said that they experienced difficulty getting into and out of cars (298, 299, 309, 316) and some of the carers stated that they found it difficult to lift the wheelchair into the car (eg. 305).

Some people reported that they used their mobility allowance towards the cost of the vehicle (299, 303, 305, 306, 308, 309), whilst others stated that they had leased theirs under the motability scheme (301, 304, 310) (however the responses made indicate that there is some confusion between motability and nobility allowance). Most of these commented that they still found it difficult to afford a vehicle.

In discussion about their financial and transfer difficulties related to their vehicles it transpired that none of the participants were aware of the wealth of information produced by the Department of Transport and other bodies which advise on the choice of car, aids, adaptations and transfer techniques. They said that they had relied on their common sense or had obtained information through ARMS, a social worker, television or a friend. Most said that they thought that such information would have enabled them to have made a more appropriate choice of vehicle.

6.7.2 Public transport

All the participants stated that it was impossible for them to use buses (eg. 317, 318). None of the respondents knew of any buses in the area with tailgates for transporting wheelchairs, though most said that they thought that such a bus would be 'marvellous'. 2 people reported that they used selected tubes and train stations (eg 319), one said he had used cross channel ferry's and a few said they had flown with relative ease.

6.7.3 Taxis

25 people (including 9 people who live at Chigwell House) stated that they used taxis, though some only used them occasionally. The majority of people thought the fares were too expensive (eg. 321, 324, 330, 332) and some people said that they thought that they were charged more for their wheelchair to be carried (332) whilst others thought they were charged less because they were disabled. Most people said that they found the taxi drivers very helpful (322, 323, 331) though a few stated that they had experienced problems. Some people said they were unable to use taxis because they could not get out of their wheelchairs (327, 329). A number of people said that they did not know of adapted taxis or did not whether there was one in their area (325 - 329, 333).

6.7.4 Driving lessons/retraining

The majority of participants said that their disability was so severe that it would not be possible for them to drive even with adaptations, or they said that they felt that they would not be able to afford an adapted car and lessons etc (eg. 334, 335).

6.7.5 Dial a Ride, etc

11 people responded that they had never heard of such a scheme. 10 people said that they thought that such a scheme would be a good idea (eg. 336, 337). 2 people thought there was a scheme in Harlow, 1 person thought that there had been a scheme but that it had stopped and a couple of people said that they thought that there were plans to start a scheme (338, 339).

6.7.6 Chigwell house

The majority of the participants who lived at Chigwell house reported that they had to rely on the availability of a driver for the adapted bus/ambulance. A number stated that they had to pay petrol to use the vehicle.

6.8 Education

The majority of participants who live in the community responded that education, whether it be vocational or for pleasure, was out of the question usually because of a combination of; poor eyesight, lack of hand movement or dexterity, frequently feeling very tired and/or ill and lack of accessible transport and toilets

However, 2 people stated that they would be interested in learning, for example, VDU skills or art (339. 340) .

Those participants who live at Chigwell House stated that they are required to attend the training centre (Treetops) for training which they referred to as 'the programme'. This was said to include; computing, personal care, clothes care, financial management and cooking. A few said they did not have a choice in attending but they were bored and that the programme was not tailored to the individual (349, 353).

A few people who live at Chigwell House said that they attended the college in Loughton. Some of them said that they took subjects similar to those on 'the programme' (343, 346, 349) and some stated that they to did more specialised subjects, such as psychology (351). A few respondents said they would like to do a course or training outside Chigwell House but that transport and/or finance would be a problem (341, 342, 345, 347, 350, 352).

6.9 Employment

The majority of the participants who live in the community stated that they felt that work was out of the question for them due to feeling tired and ill, having eyesight and/or arm weakness and/or mobility difficulties (eg. 354). Most said that it took them so long to do the few things they had to do that they did not feel bored or frustrated but a few said that they missed the social aspect of work (360).

A number of the participants who live at Chigwell House said that they would like to work (363, 364, 368) two with children, another in an office, another in catering or as a car mechanic. Others said that they did not know what they could do and/or were concerned about losing their benefits or having to pay more to live at Chigwell House or that transport would be a problem (361, 362, 365, 366, 367, 369). One person had worked and had enjoyed it for a variety of reasons.

6.10 Leisure

Conversation in this area was centred around sport, community involvement, volunteer activities, interests/hobbies and books.

The majority of participants, both in the community and living at Chigwell House, responded that they were happy watching TV and/or reading, writing to friends, some sewed or knitted, did a little gardening or photography. Many said that they feel so tired and ill that it took them all their time just to do the things that they had to do and/or did not feel the need for leisure activities.

7 people said that they got bored; 'I am concerned that the lack of stimulation is bad for my brain', 'I feel time hangs heavy', 'time does drag', 'I would like to do computing to help my co-ordination I need stimulation'.

However, a number of people said that they could not think of things to do, particularly if they had poor eyesight and impaired hand movement, 'I need some stimulation to keep my brain active, I have a computer, but I don't know what to do on it, I have run out of ideas'.

Others said that they were keen to have some form of exercise particularly since there was a lack of physiotherapy and since they felt that their enforced inactive lifestyle was unhealthy and led to weight gain and complicated their condition.

10 people stated that they would like to go swimming, but some said that transport was a problem, others said that the water would be too cold and others said that they were concerned about access to the building and pool (370 - 376).

1 lady said that she would like to do keep fit but felt that it was out of the question. 1 young man said that he had not thought about it before but would like to do archery. 1 woman said that she would like to do the kind of handicrafts that she did in Pine Unit. 1 woman said that she had tried talking books but the narrators spoke too slowly. 2 people said that they would like to paint and some said that they miss being able to work in the garden.

Of the people who lived at Chigwell House, 4 said that they would like to go swimming (375, 376, 377) a few said that they would like to play other forms of sport, others said they would like to go to concerts or go dancing.

6.11 Social activities

As with leisure activities a number of people stated that they were quite content with their social life and did not feel that their disability had changed it. They responded that either they still managed to be active or they had had a very quiet social life prior to their disability.

8 people stated that they were not interested in social activities (theatre, cinema, concerts, sporting events, outdoor pursuits, visiting parks and gardens, visiting friends etc).

5 people reported that they had active social lives visiting the cinema, theatre, restaurants, being on committees etc.(380, 381, 390).

6 people said they would like a more active social life, but that;

they were dependent on others (379, 384)
and/or
that lack of transport was a problem (382, 383, 385, 388, 391, 392, 393)
and/or
that accessible buildings were a problem (384, 386, 389)
and/or
accessible toilets was a problem (380, 385, 388).

12 people reported that;

they either attended day centres(410, 413, 417, 418),

had attended them but found them unsuitable because of the age differences (407, 408, 411, 414, 415)
or were considering attending one (409, 412, 416).

10 people stated that they were visited by people from Crossroads (eg, 420 - 425). It was reported that the visits were for the benefit of the carers to allow them to shop or just take a break from a life which they find exhausting. A few people said that they had given up their jobs, and some at quite young ages, to care for their partner since there was no one else to do it. They stated that they found it stressful being together 24 hours a day 7 days a week and doing every little thing for their partner and that a volunteer visitor helped to relieve the stress. A number of carers said that they would appreciate a day off a week from caring so that they could shop or visit a friend or family member or to pursue a hobby feeling that they would be able to look after their partner better.

The majority of the respondents living at Chigwell House said that they attended a PHAB club once or twice a week, some people said that they really enjoyed it whilst it did not appeal to others. A few said that they went to the cinema and visited pubs and restaurants (395 - 398, 400, 404, 405), whilst others said that they would like to but that transport and/or access was be a problem (eg. 410, 402) and others said that they could not afford to go out (eg.397, 405, 406). A number said that they would like a more active social life (eg. 394, 399, 401). A couple of people responded that they would like a social life outside Chigwell House and have the opportunity to have a relationship.

6.12 Religious activities

The majority of people, including those living at Chigwell House, either said that religious activities were not part of their lives, but never had been, or that they were able to participate in religious activities as they wished to. Only 2 people said that their disability excluded them religious activities (427, 430).

6.13 Holidays

12 participants who live in the community stated that they felt unable to go on holiday, due to them feeling too ill, being in financial difficulty, and/or transport/accommodation etc being too difficult to arrange due to the severity of their disability (431 - 442).

17 people stated that they manage to take a holiday with their partner, family or friend/s, some said that they had not experienced any problems (443, 444, 445, 447, 448, 449, 450, 452, 454, 456, 457, 458. However transport and lack of accessible accommodation were raised as problems by some people (446, 451, 453, 455, 459).

Most said that they were not aware of the information booklets published by RADAR etc. on all aspects of holidays. Some of those who did use the books said that hotels they recommended were not really suitable for disabled people.

2 people said that they went on holiday separately from their family, these were usually on holidays with other disabled people in adapted vehicles to adapted hotels in this country and abroad, where people were there to provide assistance (460, 461).

Of those participants living at Chigwell House most reported that they managed to arrange a holiday.

Some said that they go with organisations outside Chigwell or with their families (463, 464, 469, 470).

8 said that they arranged to go with a friend or friends from Chigwell House but that one or more care staff had to go with them.

All complained that they had to pay for the transport, accommodation etc of the staff going with them so that in effect they were paying twice and that this was next to impossible on the £10 a week which most of them were allowed (465 - 472).

6.14 Information

The two areas where people wanted information was about their condition and about the financial benefits they were entitled to.

The majority of people stated that they had not been given information about their disability at the time of their diagnosis or where to go for more advice (473 - 481).

Only one person had heard of a disability information service such as DIAL. One man used to work for DIAL, answering the phone, he states that it was disbanded but that it was very useful and he would like to do that again. Others thought that it would be a useful service and some said they would like to be involved with it.

The majority of respondents said that on one had told them about the financial benefits that they were entitled to and that they had had to find out for themselves (482 - 488, 491 - 501). Participants stated that they had found about about benefits from the Citizens Advice Bureau, the Multiple Sclerosis Society, ARMS, a nurse, the Crossroads visitor, the television, and the newspaper.

A number of people reported having difficulty finding out about their entitlement. Some people said that they had been incorrectly advised by the authority and had missed out on benefits as a result (483, 493, 498). However, 2 people said that they had not experienced any difficulty and that they had been given information and advice all the way (489, 490).

A number of people living at Chigwell House said that hey do not know how to go about obtaining information (514), or where their financial benefits come from (515, 516). Some thought that they could contact an occupational therapist or the CAB.

6.15 Personal development

Many people stated that they thought that it would have been helpful to them and their families, including partner, parents, children, if counselling had been available. Many said that their families did not understand their condition, were upset, got frustrated, had to do a lot of caring but were not given any support.

7. Appendix

7.1 Housing

7.1.1 Moving house

Some people reported that they are desperate to move home:

1 A woman with severe multiple sclerosis lives in small 8th floor rented council flat with her husband. 'I feel trapped because there is only a small lift and I am afraid of what would happen in a fire. We have been wanting to move for over 2 years and are on the social services priority list to move. We want to stay in this area because we are close to my husband's workplace so he can come home at lunch time. Also I have a good relationship with my home help, am close to my in-laws, and want to keep the GP and nurses I know. We tried put these points to them but feel that there has been no discussion of housing options and we find it hard to get the information we need. A ground floor flat was suggested for us but it was at the other side of town and it was smaller, we need more not less space to store the things I need due to my disability. We were told that we were put to bottom of list. In the mean time the council fitted a sliding door to the bathroom and hand rails in bathroom which helped, but my condition has deteriorated. I asked for adaptations to the kitchen, eg the sink so that I could at least do the washing up, but the council wouldn't because I am waiting to be rehoused'.

2 One young woman lives on her own in a council flat. 'I have been on the top priority emergency list for ten months. I was allocated this ground floor flat. No one came with me to assess its suitability and the adaptations I might need. It was filthy and my family had to clean and decorate it, I couldn't do anything and we couldn't really afford it. Social Services didn't volunteer anything I've had to badger them. The kitchen is totally unsuitable I can't get in in my wheelchair, I've scolded my self badly twice. I would not be able to get out if there was a fire and when they put in new windows because the others were rotten I asked them to put the openers at a height I could reach them but they didn't. I'd like to live near my mother in a purpose designed two bedroom flat so that when I am ill someone could stay and look after me. They are trying to put me in the back of beyond - they don't appreciate that I need to be near my mother since she does so much for me. There is no specially designed housing for young disabled people but they are building a lot for older people. It must be cheaper for them for people like me to live in purpose designed housing rather than go into residential care. I have had so much hassle getting accommodation they really argue with me even in letters'.

3 Another woman lives with her husband and one adult child in their own house. 'I spend a lot of time in bed up stairs because of the difficulty of getting out of bed and to the stair lift. We would like to move to a bungalow, but because it is our own house we would have to do it

ourselves and we would find it too difficult. We asked for help and were told "you'd be lucky", they just laughed it off'.

4 A woman who had had a stroke lived with her ambulant disabled husband in a dilapidated house. 'I couldn't get upstairs so I had to sleep downstairs, use the outside toilet and wash down stairs. We are moving to a bungalow in another part of the country, we couldn't afford to move house in this area. We asked Social Services for help and advice with moving but were told that they didn't provide that sort of help'.

Some people stated that they felt that they had pressure put on them by Social Services to move, some resisted:

5 'Social Services suggested that we move but we don't want to because we brought up our family here and the family is close by and help a lot and the neighbours are good'.

6 One couple have bought what was their council house. 'When my husband had a stroke Social Services wanted us to move to adapted premises in a different area, but we have friends all around and feel comfortable in own home. Social Services frightened me, talking in hundreds of pounds, giving a poor prognosis and talking about Possum etc, and didn't discuss the option of staying at home. We decided that we would stay at home and pay to have the lounge extended so that he could sleep downstairs'.

7 'We were offered a bungalow, but we wanted to stay in the home we have lived in all our married life, a bungalow would be too far out of town, so that we would have been unable to get to shops'.

8 'The council offered me different accommodation, but the Occupational Therapist said that it was not suitable, I didn't want to move anyway, away from the area where I know people'.

Some people stated that they felt that they had pressure put on them by Social Services to move, some moved and regretted it:

9 One couple lived in a ground floor council flat which they moved to three years previously from the house they had lived in for 38 years. 'In our old house Social Services had put in a stair lift and a bath lift but I had fits on the stairlift. We asked for a downstairs toilet so that I could live downstairs as I had done anyway for six months while I was waiting for the stairlift. It would have been a better option in the first place but we were told that it was too expensive. We had a lovely garden and good neighbours and were sad to leave. The Occupational Therapist visited the flat first to see if it would be suitable and the Social Services put in a shower and ramps. The alterations to both homes must have been as expensive as having a toilet built at the old house in the first place. We don't like our new home, none of our old

neighbours are able to visit us and we don't know anyone. The surfaces are too high in the kitchen for me to do anything, we miss the garden.

Others said they had chosen to move as a result of their disability:

10 A couple moved to a bungalow when her condition deteriorated. 'No one suggested a stair lift or anything else. My husband contacted Uttlesford Social Services and an Occupational Therapist visited the new home to be and suggested the design of the bathroom and extension for eventual wheelchair use, but didn't suggest wider doors or tell us that we could get a grant for alterations because of my disability so we spent a lot of our own money. Later when we had settled in she came to see us again and told us that they could have got a grant, but it was too late by then'.

11 One couple living in their own home were having to move as a result of the wife's disability, 'it is important for us to keep the same team of district nurses, home help and volunteer care attendent. We are not receiving any advice'.

However, some people have been moved by the council and were satisfied with the service:

12 One middle aged woman lived on her own in a ground floor council flat in Harlow. 'The council have been very helpful, they moved me from my three bedroomed bungalow to here in a few weeks. The Social Services have been marvellous, they have been terrific regarding the alterations, the bathroom was adapted, the path in the garden sloped for access, an electric mounted ceiling hoist in the bedroom. They came and suggested all of it except I had to ask for a shower'.

13 'The council were very good, they moved me from Epping to Harlow to a ground floor flat which they adapted for me. 'However, the council (Social Services?) maintain that the kitchen is suitable for me since they lowered the worksurfaces, but there is very little manoeuvring space for me in my wheelchair and I have limited use of my hands/arms. So my partner does most of the cooking etc, he finds the work surfaces and sink too low and gets back ache. The bathroom was also adapted but I have deteriorated since and the adaptations no longer fit my requirements and I would have liked a garden so that I could sit outside or at least have a view out of the window'.

Three people wished to move to 'sheltered' accommodation:

14 A young man stated, 'I would like to live in a group home where I could have my own room but have help with dressing and meals etc. but I don't know if it is possible'. (He said that he has a social worker, went to a special school and attends Chigwell House for training but that no one has ever talked to him about his future living arrangements.)

15 One young woman with Multiple Sclerosis reported, 'I had to push the council hard for a ground floor flat accessible by a wheelchair, even then it was not purpose designed, the toilet was not accessible for a wheelchair. My condition has recently deteriorated and I would like to live in shared accommodation with my own room where I can be as independent as possible but where there are people who can help and support me. There is nothing in Harlow so I will have to move out of the area, even so places are hard to find'.

16 One man reported that he lives in a house, owned by his mother, who is in her 60's and ill and his brother who is also in a wheelchair. 'I am getting weaker and my mother is less able to look after me so the consultant suggested that I go into sheltered accommodation. They brought me a form to fill in and told me that it could take months to find me a place, and that there is nowhere in or near Harlow but I don't mind where in the country I go so long as I have my independence. Meanwhile I will stay in the Respite Care Unit or stay with a friend/neighbour whose house is accessible to me. I would like an accessible bungalow so that the family could all stay together, I think my mother will miss me if I have to go a long distance away, also I have friends in the area'.

Some respondents live in purpose built accommodation:

17 One man lives with his wife and young children in a house 'which is supposed to have been purpose built for us. Prior to this we lived in an "adapted flat", but it was useless. When the council were building new houses in Harlow they said they'd build one for us, but the only thing they did was put in wide doors, build a bathroom and bedroom downstairs and fit a stairlift. They didn't even put in ramps to the doors. The Council put in a shower, which was difficult for me to use and didn't take account of my wife and young children, so we had a fight to have the shower taken out and a bath put in. We weren't involved at all, we could have saved them so much money, it upsets us to see so much money wasted'.

18 Another couple in their late 30's both have multiple sclerosis. 'The council gave us an "easily accessible ground floor flat" but it had steps front and back so I was a prisoner in the house in my wheelchair. We were told 'it's that or nothing' and we lived there for a year. We had applied for a transfer but there were no properties available. Then the head of housing at Harlow council contacted us to see if we would like a Housing Association property which was being built for disabled people only to live in. We were not able to discuss with the Housing Association any features specifically for our needs. After we moved in an occupational therapist visited us and highlighted problems. We knew her because she had visited us at our previous flat and had a shower and grab rails fitted for us. It took 15 months to get ramped access to the new bungalow so for all that time I still couldn't get in and out of my home unaided. Social Services put a shower in over the bath, they wanted to take the bath out and put in a wheel in shower but the Housing Association wouldn't allow it, we also had to

wait 15 months for the shower. All the windows and window furniture is too high. The Occupational Therapist suggested electric opening patio doors so that I can get out into the garden, but we are waiting for a new grant. We need a shed with a power point so that we can charge our electric wheelchair. The Occupational Therapist has been brilliant - she's done everything possible to get things done for us'.

19 'I have lived the past 14 years with my mother in a purpose built council flat , the only thing it has is wider doors, nothing else is suitable'.

20 Another woman (in her early 60's), 'I have lived with my brother in a bungalow which was built by my family in consideration of my needs when I was in my twenties'.

7.1.2 Extensions

21 A couple, who lived in their own home, reported, 'we had handrails put at the front door, up the stairs and in the bathroom by Social Services, but he can't get up stairs or therefore the to bathroom. A stairlift was offered but our stairs weren't suitable so we asked for a downstairs toilet, they told us that if we didn't want the stairlift we couldn't have anything so we paid for the downstairs toilet to be built ourselves'.

22 'After my accident my father built a downstairs extension with bedroom and bathroom. At that time the council said that they would do if for free but they wouldn't let us comment on the design. However once the builders started we were told that we'd have to pay after all so my father finished it.

Other people were eventually provided with an extension but were not satisfied with it:

23 A woman with severe Multiple Sclerosis lives in a council house with her husband. 'We asked Social Services for an extension with downstairs bedroom and toilet/shower, we got it but feel that the design is totally wrong. Her disability wasn't taken into account even though they knew she was. It took over 12 months to build the extension and the workmanship is dreadful'.

24 Another couple live in a rented council house. 'Social Services fitted a stairlift and built on a downstairs toilet and basin, they fitted grab rails in the bathroom and bedroom and a floor to ceiling pole beside my chair in the living room to help me to transfer from my wheelchair to a chair. We asked Social Services for all these things, it took over two years for the extension to be built, the stress drove us mad, we nearly shot ourselves in frustration, those who build these things need more expertise in the needs of disabled. The council paid for it, the Social Services couldn't be more helpful - it is the co-ordination between DSS & council that is a problem'.

However, in other cases an extension was offered or provided apparently with no problems:

25 'Social Services offered us an extension to our house consisting of a bed sitting room, shower unit and toilet and we were given the impression that Social Services would pay for it. However, we decided that with the design of our house it would not be feasible and so had a stair lift but we had to wait a long time for it. We had a lot of problems with the Social Services - their ideas are good but their equipment doesn't work. So now we are moving house'.

7.1.3 Adaptations

26 'We went through three Occupational Therapists before we got any further adaptations. At first we were given a portable hoist, but I am too heavy for my wife to push me especially over the carpet. We were also given a winding bath seat but again my size was a problem. The third Occupational Therapist actually tried the equipment herself and realised that different equipment was needed. She got us an overhead hoist, but again because of my weight and spasms my wife couldn't put me in the slings. Only then was a hoist with arms instead of slings suggested. This worked much better, but we needed two, one to transfer me into bed and from the bed to the bath and toilet and one in the lounge to transfer me from my wheelchair to a chair to help prevent pressure sores. My wife was told to unhook it and move it to the room it was to be used in but it was too heavy for her so eventually we got two. We also got ranch type doors between bedroom and bathroom so that I can go through easily in my hoist. It has upset us that we have had to fight and complain so much we got the feeling from the Occupational Therapists that is was their own money and that it was not what we needed but what it cost and they had the attitude "this is all we can provide". It was only when we really couldn't manage and complained that another solution could be found but by then money had been wasted and we felt awful for complaining'.

27 'A stair lift was suggested a number of times but we only said yes when it was the last resort, we would prefer to move house, I can only use it with help. Social Services have discussed making the downstairs bathroom into a shower room and putting in a hoist from the bed out of the bedroom to the stair lift so that I can get downstairs to use the bathroom. We like the idea but have been waiting six months because of lack of funding. We would be satisfied to just have the ceiling mounted hoist to get me out of bed to the end of bed because there is very little space for my husband to manoeuvre me and he is worried that he will hurt himself or me or both of us. Social Services wanted to give us a ramp at the front door but said that we would have to pay towards it. We found that it would be cheaper to get it done ourselves than what we would have had to pay towards it. Also Social Services wouldn't put it where we wanted it, so it has not been done but since I hardly go out we do not see it as important compared to other things. Social Services provided me with rails to help me to transfer to the toilet but they

fell out of the wall one year ago and I have been told that there is nothing Social Services can do about it, I can't use the toilet anyway now'.

28 'Social Services suggested a stair lift but said they couldn't afford to pay for it. My mother saw one cheap in the paper so Social Services bought it and fitted it. I transfer to it from a wheelchair at the bottom of the stairs and crawl when upstairs. They also provided handrails in the bathroom and round the toilet and a floor raiser to lift me from the floor to the bath and ramps so that we can get in and out'.

29 'Social Services have put in a ramp and stairlift and knocked the toilet and bathroom together. I have had to fight the Occupational Therapist all the way, the back up is not good at all, it is quicker to do it yourself'.

30 'As soon as I moved in I asked for a wheel in shower since I knew a bath would be dangerous, but Social Services waited until I had an accident and badly hurt my arm until they installed it. Because of the accident I am now unable to get around on crutches and am permanently in a wheelchair, so everything they do for me from now on will be more expensive. They have put a rail around the toilet and handrails, I told them that when my legs go into spasm I would get my foot caught under there so asked for a solid board across, they didn't do it and a few times it has happened and the only way I can get my leg out is to go on the floor then it is difficult to get back in my wheelchair'.

31 'Social Services fixed a hoist to the ceiling to raise my wife, it was supposed to make it easier for us to lift her on and off the toilet but it is more trouble than it's worth and we hardly use it'.

32 One couple live in their own home which was previously council. 'Social Services would only provide concrete ramps and we didn't want them to be permanent in case we moved, so our family provided us with portable ramps front and back. Social Services provided a stair lift when my husband was still walking, now he has two wheelchairs and has to transfer at the top and bottom of the stairs. We have had problems with the stair lift footrest which is dangerous to other stair users, we are always ringing about it and Social Services get fed up with you, it is a hassle you get passed around and such a 'phone bill. At first Social Services suggested a through floor lift, but we thought that it was totally impractical where they suggested putting it so we said no, Social Services didn't suggest anything else so we suggested a stairlift because we knew someone else with one. An extension would have been better, because he has great difficulty going upstairs to the toilet because of our tiny toilet and transfer difficulties and lack of privacy, Social Services wouldn't pay for an extension and couldn't suggest a solution to the toilet'.

33 One woman was looking after her husband who had severe arthritis and alzheimers in their rented council house. 'The only problem is getting him up stairs so I asked for a stairlift and

was told that they were not for people with alzheimers, but it is not for him it's to help me to get him upstairs and to the toilet, I can't understand it, it would be cheaper than moving house, which Social Services had suggested. They take the attitude that if you have a family you don't need any other help. Help is never volunteered I always have to contact them, it is a new person every time who doesn't know us, it would be a lot easier and take less time and probably save money if one person followed us through. When I ring the Occupational Therapist asks "who told you to ring here, you have to ring a social worker first to get the Occupational Therapist". They try ways and means not to do things, for example, I asked for handrails and a ramp, I would be happy with a wooden one, they said they could only do concrete ones, but they can't put a concrete one in because the drain is in the way so I can't have a ramp at all, I find it very difficult to get his wheelchair up and down the step into the house. Social Services provided a seat over the bath for use with the shower, they wanted to take the bath out and put in walk in shower but a bath is my way of relaxing, I would crack up without it, I had to fight to keep it'.

34 'In recent years a ceiling hoist has been installed from over my bed to the bath and toilet, I had the bathroom and toilet knocked into one for this to happen. Ie asked for these changes, you have to keep on at Social Services about what you want. Social Services put an intercom at the front door and put a baby alarm between mine and my brother's bedroom so that I could contact him in the night, but it doesn't work. There seems to be no quick system for repairs, the hoist has had a wonky button for months and twice someone has been to repair it, it needs a new control box since the fault comes back, they don't seem to have one or an assistant who knows what is happening. There no follow ups, you have gaps. I used to be allocated a social worker who called every 3 or 4 months to see if I wanted anything, it was better then, they should know their clients'.

35 'Social Services put in a shower when he could still get upstairs. When he was no longer able to get upstairs Social Services suggested a stair lift then looked at our stairs and said it couldn't be done. We would have liked that, now his bed has to be downstairs in the lounge. We were after a downstairs toilet for a long time, Social Services said it couldn't be done, but it was disgusting having a commode in the front room. In the end they agreed after I saw an electric toilet on the television and told them about it. Having it has solved our problems. We asked for a little sink in with the toilet and were told no, so we have to use the kitchen sink'.

36 'Social Services recently fitted a ceiling hoist from my bed to the toilet and bath, I waited three years for it. I've been waiting three years for a toilet which will wash and dry me'.

37 A young man lives in a private house with his sister. 'Following my stroke I didn't know about Social Services but once I did I pushed them to convert a downstairs room but for two years I literally had to crawl up and down stairs night and morning and get a bath totally

without aid until a room downstairs had been converted, it took them 18 months after I had asked before they even got round to it. Now it is done I am happy with it'.

38 'Whilst in Stoke Manderville seven years ago I found out about ceiling hoists and asked Social Services for one, but was told "no" since they had no money. The consultant at Stoke Manderville was so disgusted that he wrote to Social Services and I got one within 5 months. It has been marvellous, mum had a prolapse through lifting me for all those years. For 15 years or so Occupational Therapists came but we never got anything, but the Occupational Therapist who came at the time of the hoist was like a breath of fresh air, she got me an adjustable bed and the extension damp proofed. Up until then we'd had to fight for everything, been turned down for everything and had to pay for everything. The pump broke on my ripple mattress, it took over a week to get it sorted and I started with pressure sores. When my hoist broke the Occupational Therapist was really slow to get it mended in the end I had to go direct to the company, I was completely stuck without it. I've had to find out everything for myself'.

Others appear to have been provided with suitable adaptations with no problems:

39 One man lived with his wife and two young sons in their own house. 'The downstairs has been converted into my own room, with toilet and shower. My wife arranged it for me whilst I was in hospital. Social Services helped and we received adequate information and support. The conversion suits my needs except that I am disappointed that I can't get up stairs and feel that part of my own home is shut off to me. A stairlift was not possible because of the design of the stairs'.

40 'Social Services provided a wooden ramp at the back door and the council put a concrete one at the front door'.

41 'The social worker arranged hard standing so that he could transfer more easily in and out of the car, they also provided a ramp and grab bars in the bathroom, which was already down stairs'.

42 'The Occupational Therapist arranged for ramps front and back to be provided'.

43 'Social Services put in a through floor lift and my dad has built a ramp'.

44 'Social Services provided me with a through floor lift to my bedroom and rails in the toilet'.

45 'We have found Social Services very helpful, they don't impinge but are there when they are wanted'. But 'they have suggested excessive things like a fixed hoist, you need confidence to say no'. Adaptations provided include a ramp at the door, a shower and a stairlift,

46 'We have had a stream of different Occupational Therapists who have been helpful. We have had adaptations to the kitchen, major work in the hall to move the door into the living room to make straight through access to the bathroom from the lounge, and raised the height of the electric sockets throughout the house'.

7.1.4 Chigwell House

47 One man in his early 40's stated that he had lived at Chigwell since being 16, 'I don't remember whether I had any choice in the matter. I have not been able to decorate my own room but I do have my own furniture. I would like to grow a beard but the staff and my mum wont let me, someone shaves me. I get on with the staff ok but sometimes they get on my nerves, I don't have friends here. I want to move to a bungalow or flat near my mother and can't wait to get out. The staff have not talked to me about moving out, but they are aware that I want to move'. (A member of staff told the consultant that a flat had been found for him and that he was to be told about his imminent move on his next visit to his mothers, whether this means than the man in question had been involved in decisions about moving is not known).

48 A woman in her early twenties said she has lived at Chigwell house for two years. 'Before that I was living with my parents and had nothing to do but watch television. Eventually we found out about home care assistants who got me up, dressed and bathed, but my family had to pay for them. I felt there had to be something else to do, I really wanted a job. My social worker suggested Chigwell but they only had residential spaces when I really just wanted to come in the during the day but since they had no places I took it because I thought it would help my social life, it has and I have lots of friends. It was a good decision to come here, though I like home comforts and my family. I have my own furniture and am happy except that you have these reviews, you are criticised and you feel really small. I don't know what my long term goals are, I don't know how long I will be here for'.

49 A man in his 20's said that has lived there for nearly two years, 'it was my choice to come I like it because I have independence. I have my own furniture and have put posters on the wall. Eventually I would like to live in my own place but with other people around. I get on with the staff I see them as mates but it sometimes gets me down. My friends and girlfriend visit me here I do feel it is my home I can come and go as I please and do what I want'.

50 A woman of 19 said, 'I came because I wasn't getting on well with my family. I have been here for two years and I lived in the unit for most of that time but is now I am learning to be self sufficient in one of the flats. In the flat you can only buy food etc. each week up to £15, which makes it difficult for me to manage sometimes. I get lonely because the staff wont allow the others to visit me. I can see them in the training centre but I can't visit them in their rooms or invite them to the flat. I have been used to so many people around me then suddenly there is no one. When I have been there a little longer I will be allowed to invite them occasionally.

Eventually I would like tc move to John Grooms accommodation or a council flat nearer my family and friends'.

51 A man in his twenties has lived there for 8 months, 'a social worker in hospital suggested it, I was brought to visit and liked what he saw. It was a good decision, I have made lots of friends. But it feels like a prison at times with all the rules and regulations, the are like the gestapo at times, I am not allowed to visit my friends who are living in the flats and I am only allowed to go to the training centre when I am working on my programme. I had a three monthly review they told me to pull my socks up or I would be out. Eventually I will go back to my own house which I have visited with an Occupational Therapist to look at the adaptations I will need'.

52 One woman in her early 60's stated, 'I was pushed here by my sister in law after my mother's death. I have been able to decorate my room and have my own furniture. I have friends but they have tried to separate me and my particular friend. I would like to live with my friend with support for both of us. I think about moving a lot and the staff encourage me, they suggested that I move into sheltered accommodation with an alarm and a home help etc, it was suggested that I move to Derbyshire but then I would be away from my friends. I lived in one of the training flats for a while, I think I was doing well but I was not allowed to go into the unit and see the other residents. They went out to parties and left me out because I was in the flat, I did not want to be isolated, if I was living in the community I would want friends to visit, I could invite people but I got into trouble for inviting my friend too often. I get into trouble for helping people, the attitude of the staff isn't always right, I am told by staff I am doing things wrong, it has made me depressed, the staff don't understand. Once they cleared my room while I was on holiday, I felt as if I'd been burgled'.

53 One man in his thirties had lived there 15 years, 'I can't remember if it was my choice to come here, I don't know how I came to be here perhaps through my social worker who I have not seen since. I have not really been able to decorate my room how I want but I do have some of my own furniture and I like it. No one has talked to me about living elsewhere, I have not thought about it. I did try to live in the flat but I burnt my food so I came back to the unit. I have friends here . I was happy here but now I don't get on with the staff very well I don't like their attitude towards us, I don't like the way they treat the us, if there are no domestics we have to clean the corridors and toilets ourselves. The staff are taking over, they do what they like, the staff do not treat it as if it is our home, we don't feel that it is our home, the staff just come in and do as they like and blow us. They come in the sitting area and switch on the TV, they don't ask us, the place is going down hill the staff are doing what they like, they are not attending to us as they should be. I think the residents will go mad because of the staff. I was away for a while before Christmas because I was ill and in a couple of months I was appalled at how many changes there have been, we are not allowed to go to the flats to see our friends, I

think that is babyish. We have a residents committee but we daren't say anything to the staff it would go back to the office, it is worse now than it has ever been you can't do what you like you have got to do what the staff tell you to do, you have to wash up after staff and tidy up after other residents. Each of us has a keyworker who is supposed to listen to our problems, explain what things mean, take us out and ask us what we want, but we don't choose our keyworker. I do get on with my keyworker but I wouldn't have chosen her, she's not even been in for a while'.

54 One woman in her 20's has lived there for about a year, 'it was my choice, I wanted to learn to live independently. I arranged it with my social worker who was keen. It was a good idea, I am still learning, I enjoy it, I have a few friends here. At first I did not get on with my keyworker but I do now. I have not been able to decorate my room yet but I have put up pictures and have my record player. Nothing was designed for me at my parents, except that Social Services built me a down stairs room, but they weren't helpful about providing things, I asked but Social Services weren't very happy, my mum didn't know where to buy things. Eventually I would like to live with a few others but I have epileptic fits so I would need an alarm'. .

55 A man in his late 30's said that he has lived there for 21 years. 'It was my choice to live here at the time, but it was very different, the place is understaffed, you don't have good training. You are supposed to be able to come and go as you like but I had a tussle to get a front door key. I feel independent living is not suitable for me I need people to support me, but not volunteers they could just go when they wanted to, it would have to be someone you could put trust in they would need a proper sensible contract. I would like to live in the Chelmsford area but you have to be 55 to even get on the waiting list for sheltered accommodation, everyone talks about independent living but there are no resources. I don't get help from the staff at Chigwell I go through the Spastics Society. The staff look for unrealistic goals, if you can't achieve full potential why bother, I'm not prepared to look at and act upon unrealistic goals. Chigwell provides a roof over my head and nothing else, you need things to do and enablers, it is more of an institution today than it was 21 years ago, then you could go to the governor now you can't because of red tape, the management is too remote. Money is wasted at Chigwell, it is not functional, for example; the floors, doors and light switches. The place makes me despair, I could go and kick the financial people. The place is here for the convenience of the management not the residents, you can't talk to anyone'.

56 A woman in her 60's has lived there for 23 years. 'It was not my choice, I was in hospital first, I was promised a look, but did not get one. Previously I lived in an old people's home this was the only one for younger people. More recently they have talked to me about living in the community but I don't want to be stuck in a wheelchair in one room and no one there I don't want to start disrupting my life now. I have been able to decorate my room and choose

furniture, there are no restrictions regards visitors. I regard it as my own home and have no complaints. The staff are very good, they do things they don't have to'.

57 One woman in her 40's came to live here at the age of 17. 'I was fed up of living at home, I used to be happy living here but there have been a lot of changes. I was happier when all the residents were together. I keep it to myself that I am not happy. I don't feel I could talk to the staff about being unhappy. No one has ever asked me if I am happy. I chose the paper and everything in my room. They have put other living options to me but I don't know what I think of it'.

58 One man in his 20's has lived there for 10 months. 'I was told that the only alternative to Chigwell was going into hospital, which I did not want. I was unhappy at first but I settled in and started to enjoy it, but there are changes I am not happy with. To some extent I would like to decorate my own room to give me practice. I have brought my own furniture. They say "this place is your home", but the rules have gone over the top, they say they are in our best interest. One minute it is, "it's your house, it's for you to develop", next minute there are restrictions, you don't know where you are. I don't like the attitudes of some of the staff, you are treated like a speck of dust being here affects me mentally and physically. The staff in the training centre are ok but in the unit where you live the staff annoy me the way they talk to me. They make the rules for us to live by. I don't think of it as being home, though they say "its your home" you only have some say in your life. We have collective residents meetings and they do listen sometimes. At one time I thought I would like to live alone but now I realise it might be quite lonely, I would like to live in a family unit of four mixed ablebodied and disabled people. If I was to move I feel I will be fully involved, I would make sure I was'.

59 One woman in her 20's had been a day student at the training centre, 'I felt pressurised into moving into Chigwell as a resident two years ago. I was living at home with my mum, but did not have any independence and felt I would gain that at Chigwell. I didn't get on with my key worker, when I complained about her I got further into trouble with the office and felt small. My key worker would pass my room knowing I needed help and not come in. The staff listen to other staff but don't listen to us. They have put pressure on us to move and have put pressure on the council to get us a place. It is a single bed flat in the process of being adapted. But it is too small, but because we are having adaptations we have to sign a contract to be there for 2 years. If it was more accessible we would be more independent. The house is too far from the shops, there is no post office so how will we get our allowances? The staff aren't concerned about us being able to get out and about and be independent they just want us out so someone else can have the flat. No one has discussed with us what we will do every day when we move. We are told that the flat is a Chigwell resource even though we are paying for it. We have been put in a block with all pensioners, we are not happy but we were told that if we didn't take the flat we would have to go back to the unit. We feel pressurised to take it,

because there is a lack of accommodation in Epping forest area. We wanted to move councils to Harlow since Harlow is accessible but they have had too many applications so we have to stay in Epping Forest area. We can't wait to get away but are a bit frightened, we feel sorry for any new residents'.

60 One man in his 20's was told about Chigwell whilst at Stoke Manderville. 'I did not have much choice, it was Chigwell or hospital. I had a look round but didn't see any staff. I saw the training centre and the flats and thought I would be living in a flat, but I had to live in the unit for six weeks. My parents offered to swap their 3 bedroom house for a council bungalow so that I could live at home but the council said "no". There was no mention made by the Social Services of looking for an adapted flat or bungalow or getting one adapted. I've been living in the flat for 2 years. They say its your home but they never include you, they run it as a business, we are called 'residents', it is our home, they work for us, but is is becoming like a borstal. We get no decision into how it is run, there used to be a residents committee but we stopped because nothing was listened to. The place should be run by Occupational Therapists, the social workers always know best. The Chigwell flats are being changed in how they are run, we have to sign a tenancy agreement, friends can't visit for a whole month to prepare us for the outside world where we wont get any visitors. The office staff have decided it, it has upset our friends who used to spend time with us. We were just told, we had no say in it, we can only go to the unit once a week to pay the rent and put in a food order. We signed the contract just not to get into trouble, we are told we are childish and negative, I don't know if they are legally binding contracts, they not even on headed paper. Every three months they review your situation and progress. It used to involve an Occupational Therapist but now we are just surrounded by social workers and there is a lot of pressure. We used to write a report of what happened to us but not now the staff write it. No one from the training centre contributes, it is a bit like a school report that goes on file. I don't know what we're supposed to be doing, we have been complained at because we are trying to be ordinary. If our parents say anything at the review the staff argue. The staff in the unit don't help us to achieve goals.we are set in the training centre. We are told what to do not how to do it they have meetings and dish orders out'.

7.2 Aids and equipment

61 'No aids have been provided I have provided my own grab rail in the outside toilet'.

62 One gentleman lives in the property of the school he works at where various adaptations have been carried out for him by the school at his suggestion. 'After a number of years I wanted to find out if there was anything else I could have so I phoned an Occupational Therapist, it took her nine months to visit me and she couldn't suggest anything else except a radio controlled

door opener which I subsequently got. But it doesn't lock the door and I am concerned about security. It took 8 months to get it fitted'.

63 'I asked a bath aid we found out about through the Multiple Sclerosis Society magazine, one had not been suggested. They provided it but I didn't have an assessment'.

64 'I was provided with an Aquajack to help me bath, but I can't use it because of my spasms. It is still in the bath so it is difficult for my husband to bath. No one has asked how I get on with it or has made any other suggestions'.

65 'I have had two very helpful Occupational Therapists who got me walking frames and other aids like a bath aid'.

66 'The district nurses gave us equipment for the bath and wheelchairs etc, they have been very helpful, we haven't had to ask, things have been offered, we've had a chance to discuss things'.

67 'Social Services provided me with a bathseat, mobile hoist and a special air bed'.

68 'Social Services are very helpful, they don't impinge but are there when they are wanted. For example a social worker suggested a special bowl on a stand for washing her hair, they have suggested other things, eg a mobile hoist, but when we found it no use they took it away'.

69 'I was given things for the kitchen and an attractive easy chair with an electrically raised seat so that I could have a change from my wheelchair. I have been able to discuss the various solutions and things have been my choice, nothing has been forced on me.

70 'We are full of praise for Social Services. The Occupational Therapist has suggested all sorts of things that we would not have thought of and brought things for us to try. They have discussed a stairlift with me and we are waiting for that to arrive. A bath seat was brought but I couldn't use it so an Aquajack was brought. I am getting new taps and I was told to contact British Gas about the cooker so someone is coming to see us from there'.

7.2.1 Communication aids

71 'I have an intercom which is supposed to open the front door, but the control was put in kitchen and I sit in the lounge, it takes me as long to get to the kitchen as to the front door, I try to hurry and sometimes fall, also it doesn't work properly, it doesn't open the door, I want it mended and re-sited but I can't get hold of the Occupational Therapist'.

72 'I have an intercom/door unlocker, but the buttons are small and you need three hands so I can't use it'.

Alarm systems:

73 'On a few occasions I have to go out and leave her, so we would be interested in a help call system but who would she call? She has no strength in her fingers or her voice'.

74 'I would like an alarm so that I would feel safe when he's gone out, but I don't know anything about them or where to get hold of them'.

75 'I tried to get an alarm through Social Services in case I fall but they said I had to be of retirement age, I heard of it at the day centre'.

7.2.2 Wheelchairs

76 'I have not had an assessment for my indoor or outdoor push chair'.

77 'I was just given a wheelchair, no advice, it is an indoor one and not comfortable I get pressure sores'.

78 'I was given two wheelchairs, one for in the house it is very uncomfortable so I transfer to the house chairs but at least I can get about in the house. Someone has to push me in the outdoor chair'.

79 'I was just given a wheelchair with no assessment it was attendant propelled so I couldn't manoeuvre myself and my wife couldn't push me, then they changed it for a self propelled chair, I don't know if it's for in or outdoors. My feet won't go on the footrests'.

80 'In 20 years I have never had a proper assessment even though I have been with Stoke Manderville all that time, but it is ok, it suits me'.

81 'I was just given a chair, I can't remember who by, I can't remember if I had an assessment but I am satisfied'.

82 'This wheelchair is new to me since been coming to Chigwell for Rehabilitation, the Occupational Therapist recommended it, she produced it from somewhere, I am satisfied with it apart from cushion, I have raised the problem and the Occupational Therapist is coming to visit about it. I didn't have an assessment at St Loys (training college) even though I went in walking and came out in a wheelchair'.

83 'I had a private outdoor powered chair but I lost confidence in it because it has broken several times. Social Services or the GP will only supply a power chair for indoors, though you can get one if you give up mobility allowance. So now I have a DSS push chair, I don't think I had an assessment for it, so I can only go out with people who can push me. The after care service is not very quick, I have had to wait up to 6 weeks for a repair. My indoor self

propelled chair is very old but very comfortable, it is the right height. I nagged and nagged for this particular chair I think they gave in to shut me up.

84 'My wife has an easy chair on wheels, with lateral and head supports, therefore it is comfortable, we think the design is poor but it is better than a wheelchair'.

85 'I was given a wheelchair, and I was given it because it will go through the doors in mum's house, no measurements were taken of me but I am happy with it'.

86 'I was given a spenco cushion by the Occupational Therapist, it is ok but you are not told about the different types'.

87 'I chose my wheelchair, it is comfortable and easy to propel and folds to go in the car'.

88 'I bought this self propelled one which I use in the house, I didn't know where to get one from and I understood that there were waiting times so I went to a place in Takeley that sells them, I saw about it in the local paper. I didn't have an assessment, I was surprised that they were so expensive so a chose one of the cheaper ones. Then through my reading I was advising other people in the Parkinsons society to go to the Social Services but I had not done it myself, so I phoned them up and someone volunteered to come and see me, that's when I go the adaptations, and a push wheelchair. I was told to phone St Margrets and I gave my height and weight over the phone and a delivery driver dropped it off, no one has ever followed it up, it is comfortable but I can't manoeuvre my self but it is useful for holidays, my wife can push me. I would really like a battery one but they are too expensive.

89 'I bought an electric wheelchair from 'shop mobility, it is too heavy, difficult for me to control and uncomfortable, it was a waste of money, it clutters up the hallway. I also have one which my partner pushes, I was assessed for it and got it from Pine, it is ok and it folds for transporting they also gave me a gell cushion'.

90 'I am buying an outdoor electric wheelchair though mobility, it will take me three years to pay off, so there will be nothing left for if I want to use other transport eg taxis. It is too big to go through the doors in the house, so I also have a self propelled one for in the house, but that makes me too low to use the kitchen units etc. I was assessed for a wheelchair five years ago but I have deteriorated since then. A new chair was brought my home and they checked that it was ok for me. I have to find the money out of other benefits to pay the £100 insurance, if not and I get a puncture and can't mend it myself, which I can't, I would have to pay a £45 call out charge'.

91 'I have an indoor electric chair, but I use it in the garden in summer, it is a child's one to go through doors, I was assessed for it at Addenbrookes. It's very old I need a new one, but I

can't get hold of an Occupational Therapist. Not all ambulance people will take it when I need to go to Pine'.

92 'I've had my wheelchair a long time, 27 years, the cushion makes it too high for me to reach the wheels properly to propel myself, which I can only do with one had anyway, I would like to transfer and sit in the easy chair because I do sometimes get sore'.

93 'My wheels are my legs, I got sent a health service chair for a fortnight to try and it was modified to suit me, now it is old but there is not now an equivalent health service wheelchair. There should be an equivalent of the AA service for wheelchairs, maintenance costs for a wheelchair are horrendous and you cant afford to spend all your mobility allowance on a wheelchair there would be none left for taxis. If it breaks down and maintenance is poor you have to wait three days, if you beak a leg it would be attended to the same day'.

94 'I used to have a have small electric wheelchair which I could manoeuvre into the lift and so into garden, but now I am so ill I need a big reclining chair and I can't get it into the lift myself. I did have assessments for the chairs and they have been comfortable. I have been given a roho cushion and a sheepskin'.

95 'I have two, both suggested by the health visitor, she got me the forms, I went to Chelmsford to get measured. If anything goes wrong with it I can 'phone Chelmsford. I am happy with them. I have a special cushion, I don't know where it came from'.

96 'I was assessed for both my self propelled indoor and outdoor wheelchairs and am happy with them, I also have a frame'.

97 'I went to the wheelchair clinic through the GP and had an assessment, I am satisfied'.

98 'I went to Holly House, Epping, for an assessment, it was well worth it, I hadn't been assessed for my previous wheelchair, it was dumped on the back door step, it was very uncomfortable. If anything goes wrong with the new one I just have to ring them up. I asked to have one in a new colour and I got red one'.

99 'This wheelchair is from the hospital, I have had an assessment every 6 months and am happy with my chair, I have also got a relaxing chair'.

100 'I had an assessment, Chelmsford wheelchair centre is good. The repairers will come in 2 to 3 days. It does get uncomfortable sitting in one position, in the wheelchair all day, I can't transfer to a chair, it is too low.'

101 'My wife had an assessment at the wheelchair centre in Epping, they were very helpful and tried different sorts, the one they gave her she can virtually lie in, we didn't have to pay for it

but she got it too late and has not been able to use it. Her previous one was an ordinary one, standard, they just brought it and it was not comfortable'.

102 'I was assessed at Stoke Manderville and got a good one'.

103 'When I gave up my callipers I had a proper assessment fro my wheelchair and am happy with it'.

104 'It has been purpose designed for me but it is a push chair so I can't manoeuvre myself, it is reasonably comfortable'.

105 'I had an assessment I am happy with it, it is comfortable'.

106 'When I became immobile I asked my GP about a wheelchair, I had to apply to Brentwood, they sent a form for my measurements to be signed by my GP. I could propel it to start with but when I couldn't my GP suggested an electric chair. I was assessed for an indoor chair only and I can operate that, I spend most of my day in it, I had to ask for a special cushion to stop pressure sores, I would like a headrest. I have a push chair for outside.

107 'I had an assessment but still got just a standard wheelchair and had to wait twenty eight weeks for it when I was told it would be three. I had to 'phone every week. We both have wheelchairs, mine is comfortable and functional, his could do with a leg extension.'

108 'I had an assessment at home for my indoor electric chair and they gave me a wedge seat for my back but I felt as if it was throwing me out of the chair. It is not comfortable, I hate sitting on plastic. I can get in touch with them at St Margrets wheelchair centre and ask them to come back. I also have an outdoor electric chair on loan from the Multiple Sclerosis society and I have bought a scooter'.

109 'I have had a number of assessments and changes at the hospital for wheelchairs; I have one I can propel myself, but it is too wide to go through the doors, I was given another indoor chair which I manoeuvre by pulling self about with furniture, it doesn't manoeuvre very well, it sticks on the carpet, I fell out once'. The Social Worker had one of the easy chairs raised on blocks but she can't transfer out of her wheelchair into it.

110 'I have a battery powered chair but it is not comfortable, I have been to Addenbrookes for an assessment, I would like one with big wheels that can be propelled with one hand, I could get around better with one of those than with the electric one but you can't have two chairs. My wife is quite light and finds pushing hard so we hire an outdoor electric chair when we go away'.

111 'I got an indoor electric wheelchair eventually, I was supposed to get it in July six weeks after the assessment but finally I finally got it in the November. I do use it but my hands are

a problem. I also have a push one for outside, but they took the footplates off it when I was in hospital, I don't know why, then they stuck something silly on and they don't work properly'.

112 'Nobody tells you about wheelchairs, which is best one, they just tell you what you need and that is that, I had a full assessment but I still feel it is wrong for me. I had an electric and a push chair but now I can't use the electric one'.

113 'My wheelchair is my legs. I have an electric one which I was assessed for and given for free. But I was slimmer then, I have put weight on because of my inactivity, so I am having trouble with it now and have a sore bottom because it hangs out of the back and rubs against the bar. I have tried a variety of cushions. The problem is with the wheelchair because there are only three Department of Health ones to choose from. I have tried using mobility allowance for a different chair but I was told it would be £3500 for a chair, then I would not have any mobility allowance for taxis etc. I was told to ask charities, I tried them but without luck, not everyone in wheelchairs can sit in the same three and not everyone can afford £3500. It is a problem just finding out where to go, to get past people, there is a lot of book passing'.

114 'After my assessment they first gave me an old heavy thing,after a big argument I got a lighter one that folds. Mum can keep the other one at home for when I'm there. I would buy one for myself but it would be £1500 how am I supposed to afford it, why are they so expensive?'

115 'Since I can't propel myself I have been assessed for glider chair' 'walking' with it is exercise. I was never assessed for my wheelchair which is uncomfortable, I have used one for 35 years and not had a new one for 20, I would like an electric chair but the house is too small'.

116 'The wheelchair comes from St Margrets, I had an assessment but it is too tall and I can't reach the floor but it is comfortable'.

117 'Since I am totally paralysed I need an indoor/outdoor electric wheelchair to get to work. This one was supplied recently by DAS, my employers had to prove it keeps me in a job, it took a lot of convincing. In the letter I received they told me not to use it at weekends, evenings and holidays etc! I went to the Keep Able centre for it and am happy with it'.

118 'I have an appointment for an electric wheelchair, I am told you can only have an electric wheelchair for indoors not outdoors but if I did have an electric wheelchair for outdoors I could be independent. I would have to buy it myself. I was sent a form for an assessment for an electric chair they wrote back to say they couldn't help because the Occupational

Therapist put on that I needed an electric wheelchair for shopping I didn't even see her. Now I've got an appointment I'm going to ask for an indoor electric but will use it for outdoors. I need a new manual chair, or at least it mending, one arm is broken and is fastened with sellotape but they wont give me an electric and a manual but I need both because when the electric is on charge I still need to move about, eg to get to bed'.

119 'I have a self propelled chair, I am happy with the chair, I couldn't afford to buy one. I would like a brighter one. Getting a comfortable cushion is a problem, I get pressure sores, I would like a special cushion but I would have to buy it myself and now there's no Occupational Therapist here how would I get one anyway?'

7.3 Personal care support

120 'I have to do everything for him, change his pads, everything, I wouldn't want anyone else to do anything intimate for him, I wouldn't trust them'.

121 'I have a strip wash at the kitchen sink down stairs (the toilet is downstairs) because I can't get upstairs, my wife helps me to dress'.

122 'My husband has to help me to the toilet, I have to use the outside one since I can't get upstairs. He helps me to transfer from my wheelchair to the toilet. We have been given a commode but because of his injury to his leg and foot he can't help me to transfer to the commode because it is not stable. He helps me to wash and dress. He washes my hair out in the garden'.

123 'My wife puts me to bed, dresses and undresses me, I go to the toilet alone, she baths me. My wife asked for help for two weeks while she went on holiday but the GP nurses could not come until 10 am so my daughter did it. My wife is annoyed because it would have cost more to put me in hospital for 2 weeks'.

124 'I or occasionally one of our daughters lifts her on to the toilet. I wash her because she is frightened in the bath and the purpose built extension is cold (3 outside walls). The design doesn't facilitate easy showering, Social Services put a bench on the wall for her to sit on but it is useless, the shape is wrong and I end up getting wet, so mainly I give her a strip wash. The nurses used to come to bath her but they said she was not ill and said I was capable of doing it (she has very sever multiple sclerosis and can not even lift her hand and he has osteoarthritis) so I do it'.

125 'My husband (also in his early 60's) does all my personal care tasks, I don't have faith in anyone else. He has had no guidance on lifting which he feels would be advisable. Eating is very difficult, we have tried different cutlery but have not found any which helps. I need an

enema once a week, the nurse showed my husband how to do it so he does it, he doesn't mind'.

126 'My wife can't help because of a very bad back, she has been in hospital with it and has to be very careful so my son in law helps me with bathing. I can just about still manage to transfer to the toilet. No one has ever asked, like you are (referring to the consultant) how we manage, we would have appreciated that'.

127 'My husband helps me with my shower but he has a heart complaint and shouldn't really do it. There are no nurses for bathing, they used to do it but not round here anymore. My husband helps me to the toilet, I have a catheter but it is still a two person job'.

128 'My brother is my carer (they are both in their early 60's) but I have others for back up which is important, he shouldn't be a 24 hr carer he needs a life of his own. Using the hoist I can bath and use the toilet alone, but my brother gives me a hand sometimes. The hairdresser comes to wash my hair. The District nurse bathed me until my brother took early retirement last year to help to look after me.

129 'I can only give him a strip wash, it is hard work for me, I can't wash his hair because he can't bend his head. I would like outside help and support but none has been offered. He only has a bath and has his hair washed when he goes into Pine. The district nurse can't come to bath him until 9am at the earliest, this is too late he has to be got up by 7am. I have asked if he could have a bath at a local old people's residential home where they have the proper facilities. I would push him over, but they wouldn't be covered for the insurance so that is out'.

130 'My mum gives me (son in his 20's) a bed bath'.

131 One young couple who are both disabled said, 'we feel that we need someone there in case we fall since we can't help each other, hair washing is difficult. The home help has offered to help but she has only got limited time, no one has suggested a nurse'.

Home helps or personal care assistants:

132 'My live in older partner (pensioner) does most things for me. The home help gets me up every morning except weekends when my private nurses come in and the private nurses put me to bed every evening at 9.30 (when the home help did this I was in bed by 7.15pm)'.

133 'My husband does most of my personal care. But the home helps gets me up and washed, puts my pads on, I can dress my top half, they do the rest. Since I am on my own for most of the day I wear pads and sit on one in my wheelchair, I.have a commode in the living room

but I have difficulty transferring to it. I saw a continence adviser who suggested an intermittent catheter, my husband sees to it for me, but now it doesn't make any difference'.

134 'My husband gets me up, washed and dressed and gets my pills ready before he goes to work. The home helps put me on the commode and changes my pads. He turns me in the night'.

135 'I (husband) take her to the door of the toilet then she can can manage. I have been told that I am not allowed to bath her, the home help comes every morning to do this and she can manage with the Aquajack, but I can't have a bath because of it so I have to shower. My wife has difficulty eating, she was given cutlery by the Occupational Therapist but she still has difficulty, it has not been followed up'.

136 'A nurse comes in to look after me each day. She's been coming for 10 years. When I was first ill she came less often and for a shorter time as I gradually became more ill the nurse came more often and for longer. When I was first ill the consultant contacted my GP and said that I needed nursing, the nurse came and assessed me and from then on she has come daily to see me. We have built up a relationship and I feel confident. Because of my grafts I can only sit up for four hours a day so the nurse gets me up by lunch time, washes and dresses me, gives me lunch. Then a paid nurse comes at 4pm to put me to bed. This was arranged privately through the GP clinic after seeing a notice in the surgery'.

137 'My husband helps me with everything but the home help also helps with bathing, he is not allowed to bath me alone we don't know why because he does all other heavy lifting. Because of the difficulty of getting downstairs to the bathroom he sometimes just washes me upstairs and I use the commode next to the bed. My husband looks after me 24 hours a day he feels it is forced on him and is very frustrated'.

138 'My wife helps me to get on the toilet with the hoist, I have a nurse for washing, she gives me a bath every two days. Social Services suggested a nurse, she's been coming for a year, I pay out of my allowance'.

139 'My Mum helps me to go to the toilet, the district nurse comes in every week day between 9.15 and 9.45 to give me a bath, except the days I go for rehabilitation when that would be too late, so I have private nurses then and at the weekends'.

140 'Twice a week the home help helps me onto the shower seat then I can wash myself, I need someone there to give me confidence. The home help is terrific. I found out about her through the rehabilitation centre (Chigwell House) before that I managed, but not too well'.

141 'I use a bedpan down stairs because my mum (80) is too frail to help me upstairs. Recently I have had had a 'personal carer' every morning paid for through the Independent Living

Fund, they get me up, dress, wash or bath me, give me my breakfast. We found out about it through the home help, before that it was a real struggle. They come in evening to help me going to bed or I pay neighbours to help. Before that mum and my sisters struggled'.

142 'For years my mum did everything and the lifting gave her a hernia, the nurses wouldn't help but as mum got older we insisted we have someone, eventually we got a nurse to help mum, they come very late sometimes but they are more or less ok. Mum washes my hair, she's a diabetic and has high blood pressure, she's had a mini stroke but she still has to help the nurse. We asked for two nurses to come, they argued and said we couldn't have two nurses that the other person would have to be from Social Services so we asked the home help if we could have 'home care' in the meantime we paid an agency nurse, but we couldn't really afford it. Eventually Social Services said they had some one who could help the nurse two days a week so we carefully explained that she had to come at the same time as the nurse, but since it was lunch time Social Services said she couldn't come at that time even though the woman herself was happy to come then. Eventually we got it sorted out but only for two days a week. I have just found out about the Independent Living Fund (from Stoke Manderville), I had been paying out of my own pocket for the nurses, so that might solve it'.

143 'I need 100% support for dressing, bathing, tooth brushing etc. I have had a series of foreign students looking after me, but I got fed up of it and phoned Social Services and told them I'd managed so long without bothering them but really needed their help now and quickly because of my circumstances, they said they couldn't help at all and gave me some addresses for nurses. I phoned them but it would have cost me more than my salary. I need someone to sleep by me, everything. I have found a handyman member of staff to do the job, it is satisfactory in as much as he is here but it has been a struggle to teach him what I want him to do. Social Services have shrugged their shoulders of me I thought they were supposed to be there to help'.

144 'I can go to the toilet and shower alone, the home help comes weekdays 8.30 to 10 am to get me up and dressed and do my housework. I pay out of the Independent Living Fund for someone to do what I can't do and put me to bed in the evenings and get me up at weekends, previously a friend did it'.

7.4 Domestic support

145 'I did get help with shopping, housework etc when I was alone, but now I have a partner that has been withdrawn (he is a pensioner)'.

146 'We had home help when I first came out of hospital because my husband was also convalescing after an injury, but we stopped it as soon as possible because we had to pay for it and we couldn't afford it'.

147 The husband does all the housework, shopping, laundry, preparing meals, feeds her, 'I would appreciate a home help because I am not a very tidy person and would welcome a break, I asked for help but was told I would have to pay for it or they would take it off attendance allowance. I had lost my job and so we are short of money, we're on income support. I tried having a private cleaner in but couldn't afford it. I feel I have to crawl for help in that area'.

148 'We have never been offered help in the house even though my wife has a bad back, I can't do anything to help and she has to keep going to work because we can't afford for her not to. The GP says she shouldn't be working but how would we live with the mortgage to pay? Our daughter does the shopping and gives me lunch whilst my wife is at work'.

149 'My sister does it, my father does the shopping, I do the laundry myself and cook my own meal in the microwave'.

150 'We don't feel we need a home help (despite mum having high blood pressure and a slight stroke and a middle aged daughter totally paralysed from Spinal Injury and a middle aged son with Huntingdons disease to look after)'.

151 'My mother is happy to do it for me so long as we live close together, no one has talked to us about what is available I have not been offered a home help but I wouldn't want it'.

Other people receive a variety of help either free or paid towards partially or totally:

152 'Two home helps come together every week day to get me up and do some house work, but they don't have much time when they have finished with me. We pay something towards the home help, we would like them to come for longer so that they could, for example clean the bathroom, they only have about 10-15 minutes left for cleaning, but we can't afford it'.

153 'My husband does the shopping and laundry, we have a good neighbour and I have meals on wheels, I asked my GP for it, Tuesday to Friday, on Monday's my husband leaves my lunch prepared'.

154 'One home help comes for about 3/4 hour each weekday morning to help my wife to wash and bath but she won't do anything else even if she has time to. Another comes two days a week to do the house work and ironing. They won't come when my wife is out for example at Pine or the dentist. We got home help because I asked Social Services. I think they should have a job specification so that the client and the worker knows what they are and are not allowed to do, they should be more flexible, if they are done in 1/2 an hour they leave, even though they've got another 15 minutes to go and there are other things that need doing'.

155 'The home help comes every week day for about an hour to do the house work she comes at convenient time for me, but I didn't have a say when it would be. To get one the consultant got in touch with the social worker to get things moving'.

156 'The home helps come weekdays about 11/2 hours per day, but I would like it to be more flexible so that they only had to come when I needed them. My husband does the shopping, laundry, prepares meals and helps to feed me'.

157 'The home help comes for about 4 hours a week, she is more like a friend, has a cup of tea and a chat, that is better for us than her dashing around with a hoover. We didn't have to ask, it just evolved over time, the home help organiser keeps in contact, she phones up and asks if everything is alright'. Her husband does some of shopping and feeds her, and the crossroads lady does the ironing.

158 'My mum does most of it, but she is elderly and when she was ill once the GP suggested a home help once a week to do the heavy work'.

159 'Though I am unable to do anything and my mother is 80 we only get home help for 1 hour a week, it is not enough. We pay other people to clean the windows wash the curtains etc. My sisters do the heavy shopping'.

160 'The home help comes twice a week for 11/2 hours each time, we can say what we want her to do. Now my husband has given up work to look after me we suggested that the home help could stop but they said they would keep coming. My husband goes shopping and makes meals, I can do a few things'.

161 'The home help comes twice a week, it was arranged through the Occupational Therapist. The home help organiser called and asked what types of things we needed; shopping, ironing, getting allowances, et, She is more of a friend now. I am often too ill to cook so we don't eat properly, just cereal for our main meal some days, or we keep food in the freezer and microwave it. We wondered about meals on wheels, but would we qualify since we are in our thirties?'.

162 'I had meals on wheels once when my wife was away, I think she arranged it through the surgery, it was satisfactory'.

7.5 Health care

6.5.1 General Practitioner

163 'My GP likes me to go there if I can but the surgery not accessible'.

164 'My GP gives me adequate support and advice, the surgery is not accessible but I go and they help me in'.

Some were very pleased with the treatment from their GP:

165 'My GP is good, I get lots of advice and help from her of a social nature as well as health, except that she didn't advise me on continence because she thought the consultant was doing that but she wasn't even though I'd told her I was incontinent'.

166 'I have a very good GP I've been given good advice and information and he is supportive to my mother'.

167 'My GP is good, he tells me I'm doing a good job and this encourages me, I have talked a lot to my GP and her refers me to people'.

168 'Our GP is helpful and supportive but he has no knowledge of my particular disease, I am treated and given drugs by a London specialist and the GP doesn't interfere with that but he does treat other ailments like a chest infection'.

Other people are less satisfied with their GP:

169 'My ex-GP wasn't very good and he recently dismissed me from his list, my new GP is much better'.

170 'I am not really satisfied with my GP, he comes if asked but he doesn't visit unless something is wrong, I think they should come regularly just to check'.

171 'I am very disappointed with my GP, because I'm disabled he doesn't really bother with me, I've had tummy troubles, urine problems, back trouble, but they've never been properly investigated. It is a very poor service'.

172 'The GP comes every three weeks to see how I am but she is useless, she knows nothing about Multiple Sclerosis, she doesn't talk to me but to my husband, she acts as if I can't hear or understand or have my own opinions. Every illness I have is put down to MS, nothing is properly investigated. She changed my medication later I found out from the hospital that I should have had blood tests before using that medication but I didn't. I've never been given any information or advice by my GP'.

173 'The GP is good but he can't understand my speech since my stroke. He visits me but has never explained the stroke or asked me how I manage'.

174 'My GP is useless he comes to my home but for example with the recent flu I had congested lungs and needed physiotherapy but the GP wouldn't arrange it he said my mum had to do it'.

175 'My GP thinks that everything that's wrong with me is down to my Multiple Sclerosis, but if I call him out he always comes'.

176 'Our GP is very good, like one of the family, but every illness is put down to Multiple Sclerosis eg a cold, a tummy upset. We read up about our conditions and tell our GP'.

177 'My previous GP didn't tell me anything and I had known him from being 7 when I was diagnosed with Friedreich's Ataxia. I recently changed my GP and am happier, but other than my disease I have never been ill'.

Prescriptions:

178 'Repeat prescriptions are a problem, you have a card have to write them on, it has to be taken to the Doctors and left in a box, then you go back the next day for the prescription and it take to the chemist. Before you could 'phone for a repeat prescription which was better'.

179 'I can't get free prescriptions, because of my husband's finances, he has redundance money from a previous job, I would like to have free medication on my own merit'.

7.5.2 Hospital experience

180 'When I went to hospital with my scold they didn't even get me out of my wheelchair, they just put a dressing on what they could see, I didn't know and they didn't see that I was also scolded round my back, they wanted me to go back every day for dressings, but how was I supposed to get there?'

181 'When I first saw the consultant about my MS he made me feel a fraud, he shouted at me for using crutches and walking strangely but I couldn't walk any other way'.

182 'The centre for Parkinsons at the Middlesex is great except that the nurses will not allow you to self administer your own drugs, but we have to learn to be responsible for them, that was a real fight'.

183 'I can't stand the hospital at Harlow, the staff are so rude. I had a slight stroke, they made me feel guilty that I was taking a bed. I made myself better doing exercises, I didn't get any physiotherapy but because I had been a P.E. instructor I knew what to do'.

184 'When I was in hospital for an operation I was made to feel a nuisance because I am disabled as well, the staff couldn't cope'.

185 'When I came out of hospital after my circumcision I wasn't given any advice, my wife rang the hospital for information since I'm in a wheelchair and about bathing etc the nurse just laughed'.

7.5.3 Nurses

186 'I have a very good relationship with my district nurses, it is a very good service. I am catherized and have problems with it, I saw a continence nurse but she was not very good I am still having trouble'.

187 'I see community nurses but not on a regular basis, they bring my pads. I saw a continence adviser she gave me exercises, they are not easy to do in a wheelchair, she didn't suggest pads'.

188 'I telephone the nurse to come about my catheter about every 3 months'.

189 'I saw a continence nurse after my stroke while still in hospital, she had come to see the patient in the next bed, when I recovered from the stroke I woke up with the catheter, no one told me that I had it or has explained about it or why I have it'.

190 'The district nurse brings me continence stuff to try, but it is very expensive, I used to buy at chemist, I hunted through journals to buy it in bulk. The continence adviser was useless, I was not satisfied'.

191 'The community nurse comes every two weeks to see to my catheter, I have to 'phone up in the morning to arrange it, but I have to be quick because I can only get them between 9 and 9.15am, they moan about it as if it is my fault'.

Some people are dissatisfied with the nursing service:

192 'The community nurses used to come twice a day at 10am and 3pm to wash and dress my wife but the services were withdrawn cause said she wasn't ill, so I suggested that my wife go into care during the week and I'd bring her home at weekends so that I could go to work, I didn't want to but I felt I needed to work and there is no one to look after my wife, I hate to leave her, but the nurses thought that was dreadful, so I don't work and I look after her'.

193 'The community nurses told me they were too busy to come, I had to go into hospital because the nurse didn't come, I used to have a nurse for a bladder wash out but now it is being stopped because others have said that it doesn't benefit them, but it does me but I'm not being given any choice. They tell me to 'phone if I have any problems with my catheter, but sometimes they don't care'.

194 'We arranged for the nurses to visit me once a day while my wife was on holiday just to check that I was alright. I told them where my needles were and asked them just to stick one in me if they came round and found me on the floor, it might have been that I had not been able to get to them in time. They said they would not be allowed to do that and that they would have to call the emergency services. I thought that was ridiculous, acting quickly would be better for my health and safer for me and cheaper than calling out the services'.

7.5.4 Dentist

195 'Information on daily dental hygiene would be useful because it is difficult to brush my teeth myself'.

196 'I do not go because I have not been able to find one on a ground floor'.

197 'In twenty three years I have been trying to find a dentist where I could stay in my wheelchair, then a year and a half ago I found out I could go to Loughton clinic, my nurses are based there and they never told me'.

198 'There is no accessible dentist in Epping so I went to the hospital dentist. The clinic in Epping does childrens teeth but they didn't want to know disabled people'.

7.5.5 Opticians

199 'I think I need to go but where can I go, how can I get there?'

200 'I can't get there, you could do with domiciliary opticians'.

201 'I could do with my glasses changing but transport is a problem'.

202 'I went to Moorfields, there is nothing they can do, I have a low vision aid, I do use it but it is tiring'.

203 'I saw an optician in Pine, I was told there was no point seeing an optician again and not to bother going to my own opticians, but I would like to have them checked once a year, it would give me peace of mind'.

204 'The hospital optician made an appointment for me to be there at 9.30 but I am not capable of getting up by then and getting there, he gives me drops'.

Comments from people living at Chigwell:

205 'I phoned the officer and asked to make an appointment to see the optician I was told I had got to see my key worker about it, but she's not been in for a while'.

206 'I've never seen an optician but I can't read small print'.

7.5.6 Chiropodists

207 'They used to do home chiropody free for disabled people and I had that but now that has stopped so I goes private but I feel I should have it free so I am trying to get it again at the surgery'.

208 'I have had someone come in, they phone to say when they are coming but I might be at work, I can't always fit in with them.'

209 'I have to pay privately - don't think it's right'.

210 'I pay a chiropodist who comes every eight weeks, I feel I shouldn't have to pay'.

211 'I go to a private Chiropodist by taxi, I feel I need more but I can't afford it'.

7.5.7 Occupational Therapy

212 'As well as giving us equipment and sorting out the stairlift we have been given a form to fill in for cheaper phone calls from BT and the Occupational Therapist arranged for the home help organiser to come'.

213 'I am in touch with an Occupational Therapist at Social Services and if I need anything I just phone her, she comes round and we talk about it'.

214 'I am still in contact with the Occupational Therapist if there is anything I need I can pick up the 'phone and speak to her and she is there in a couple of days. She phones to say have we heard of things and brings us things to try, she's come up with simple things we wouldn't have thought of'.

215 'I didn't have an Occupational Therapist but a social worker from Harlow used to drop in every couple of weeks, she told me about grants and checked everything was ok, it was useful, but when there was re-organisation between Harlow and Hertfordshire she stopped coming'.

216 'We had two good Occupational Therapists who suggested lots of things, but now there is only one part time one in the area and we've not seen one for two years despite many 'phone calls by my husband to see her'.

217 'I wanted a bath cushion because of my sore bottom, the Occupational Therapist didn't know what I meant, so I found out about it through Stoke Manderville and sent her the details.

218 'My Occupational Therapist wrote to say that she had too many on her books and has done all she can so she is not coming anymore'.

219 'After the woman from social services had been that time and suggested the bath seat and the hand rail up the stairs she wrote and asked it everything was alright and said she felt she had done all she could for me and if I agreed she wouldn't contact m again but I could if I needed her. I feel that I could contact her'.

Comments from people who attend Chigwell House training centre (Treetops), as residents or day visitors:

220 'I have never been assessed in my whole life for what I can do and what I need, I had got as far as filling in forms when I came to Chigwell House for rehabilitation then the Occupational Therapist left and it didn't go any further'.

221 'I used to have it at Chigwell but they don't have Occupational Therapists there now. It would have been marvellous to have a periodic assessment and equipment suggested'.

222 'I used to have it at the rehabilitation centre at Chigwell and they also gave us exercises, I really need exercise, they don't have any Occupational Therapists now. I feel that it is so important that I wrote to Social Services in October '91 to ask for Occupational Therapy here, someone visited in December but it is now mid-February and there is still no sign of one, he hasn't even let me know what is happening'.

223 'The Occupational Therapists at the rehabilitation centre at Chigwell tried to teach me to dress myself they got me learning how to use a hoist, I used to do exercises and they got me standing and moving, I liked Occupational Therapy, but then it stopped, we are not allowed to do the same Occupational Therapy as before because of the insurance, we lost three Occupational Therapists'.

224 'I used to have it, I made trays but I had an argument with him one day and have not gone back'.

225 'In the training centre there were 2 trained Occupational Therapists but the boss here stopped it'.

226 'We need an Occupational Therapist for lots of things at Chigwell but we don't have one anymore'.

227 'There used to be four Occupational Therapists, two qualified and two trainees, they organised the programmes, they knew all about equipment for bathing and getting dressed, now if you need anything you have to go to the office. The programmes we do in the

training centre are not continued in the unit. All the programmes have changed, now we only have instructors, they don't tailor the programmes to the individual'.

228 'I go to St Margrets three times a week for occupational therapy, I can get out of my wheelchair and stand up, I make things, I am happy with it, it is worthwhile. I suggested it, I overheard someone talking about occupational therapy at St Margrets and that it was good so I asked if I could go and I was referred'.

7.5.8 Physiotherapy

229 'I think I would benefit, except for a brief course at the Middlesex, where he also gave me advice on getting in and out of bed, etc. I have not had any. I tried to get a therapist to talk at the Parkinsons society but they wouldn't come, they were antagonistic'.

230 'After I had been going for 3 years my physiotherapy ceased without explanation. But I had never had any set exercises, I never had a programme, only after 3 months did a physiotherapist ask me what was wrong with me. Then I was ill again and the physiotherapy started again, but it stopped after four months, transport was always a problem, it was either late or not at all so often I didn't have a full session'.

231 'Through the Multiple Sclerosis Society you can have six weeks a year, but I didn't find it a help because it is group rather than individual, that would be useful. There is no neurophsyiotherapy at Harlow'.

232 'I have had it at Epping and Harlow, I feel it is essential to keep me moving'.

233 'No one has ever raised the possibility of physiotherapy - I don't know if it would help'.

234 'I used to have it years ago, but I felt it was not doing any good so I stopped'.

235 'I had physiotherapy for two years, three months on, three months off, last time I took the place of someone who had died. Now I'm in a wheelchair I have been told they can't do anything for me, I feel I need it. I have tried it privately, but at £23 per hour I can't afford it'.

236 'I have made enquiries to go on a Thursday night to a place for people with Multiple Sclerosis. They give you exercises in hospital but are difficult to do at home'

237 'Once my GP said I needed physiotherapy quickly, I asked for it on the NHS but was told I couldn't since I only needed it now and again, also getting to the hospital is a problem, so I had to pay for it. The physiotherapist needs to be on the end of a 'phone like a nurse'.

238 'I would have benefitted from physiotherapy, I need physiotherapy. I heard there was a domiciliary physiotherapist and asked for one, I was told one could come once a week for a couple of weeks, I told her not to come at midday because that's when they come to get me up and bath me, so she insisted on coming at 12, so I ended up not getting any, I feel would have benefitted'.

239 'Its never been mentioned, I think it would have been beneficial years ago, once the hospital let me go and I was living in the community nothing has been followed through. Exercise and muscle tone would be smashing now'.

240 'I used to go to hospital three times a week for occupational and physiotherapy but I had half an hour physiotherapy and sat and waited for an ambulance for two hours so that when I got home I felt no different from when I went. I've not done it for four to five years, they stopped occupational and physiotherapy, you are only allowed six months at a time'.

241 'I haven't had it since school, I think I would benefit'.

242 'I got physiotherapy through ARMS two to three times a week. I felt it was doing me good I felt different physically and mentally afterwards, but I had to pay for it and it got too much (she could not afford it). For a while an ambulance collected me and took me to St Margarets in Epping, I went in the pool. When I had to use a wheelchair it discontinued, then the Red Cross came for six visits, now I pay the Red Cross person to come privately, I have written to my MP about it.

243 'I did get physiotherapy two mornings a week, at Princess Alexander hospital but the ambulance picked me up at any time therefore I often missed physiotherapy, I complained to my MP'.

244 'When I lived in Harlow I went to physiotherapy twice a week, the ambulance collected me. The Doctors and physiotherapists never asked how I was coping with other aspects of my life. I went for five years, when I moved I continued to go for three years then it just stopped without any explanation. I miss it. I has always do my exercises at home, it means getting on the floor which is very difficult in my condition and I bump my head every time, I am concerned about the cumulative effect of this. Once in Pine I had my hands waxed for arthritis, again I was not told why. After this I went to the Herts and Essex hospital for hand waxing, but only for three weeks then I was written off. I was told to continue doing it at home, that I could get wax from my GP but how can I do it at home, I tried to 'phone the occupational therapist to get the things I need to do it at home but I can never get hold of her. I was made to feel lucky that I was getting any treatment at all and that I was being greedy, but I have paid my National Insurance and taxes for years and I feel I deserve care'.

245 'I had physiotherapy, it just occurred, I had it for two years on a regular basis, three days a week, from St Margarets, I don't pay, but the physiotherapist told me their boss can stop it at any time.

246 'I had physiotherapy in Princess Alexandra hospital for two to three years, they did exercises with me, it was good but sitting in my wheelchair for two to three hours waiting for the ambulance afterwards made me feel ill. It used to take my husband a couple of days to get me right again so I stopped going because it was hard work for him. I had a physiotherapist at home a couple of times but it wasn't very good. I feel it would be better to have massage for muscle tone not physical exercises'.

247 'I first had physiotherapy in Pine then I got in touch with Princess Alexandra hospital and had physiotherapy there for eight weeks then I was dismissed. It wasn't discussed with me they just stopped it. I felt physiotherapy did me good, I don't want to just sit and do nothing, also it was a nice break. My husband does exercises with me'.

248 'I have never had occupational or physiotherapy for my arthritis'.

249 'I used to have physiotherapy three times a week at Princess Alexandra hospital, I could drive there when I had a manual wheelchair, but now I can't drive and I have an electric wheelchair so I can't get there. The ambulance won't take this wheelchair. I felt it was doing me good. I was transferred to St Margrets but when they closed the pool I asked to go back to Princess Alexandra hospital. I was told I couldn't because of the transport problem. There isn't any community physiotherapy. I tried a private one but she disappeared. I have felt a deterioration since it has stopped'.

250 'When my wife was first ill she went to hospital for physiotherapy but transport was problem. Now she has private ones for her chest complaint, they used to come regularly but not now because there is no problem but they will if telephoned. She did have a social services physiotherapist but she wasn't any good and caused new problems'.

251 'I would like physiotherapy every day, it makes me feel physically and mentally better, I feel that it prevents deterioration. At present a friend in the village who also has Multiple Sclerosis and who can still drive takes us both to physiotherapy on a Tuesday afternoon to Walthamstow My son helps me to do exercises at home'.

252 'When I was on crutches I used to a have a physiotherapist come to the house, but now I am in a wheelchair after the accident she doesn't come any more, I feel I need it more'.

253 'I did get physiotherapy at Princess Alexandra hospital for a while but they told me they couldn't do any more for me, they told me to go back if I got worse, or they would phone me after six months. I feel I have got worse but I don't know how to go back it is well over six

months ago and they haven't 'phoned me. I would very much like more physiotherapy, I 'phoned the physiotherapists in community but they charge £26 per hour and with all I need I can't afford that'.

254 'Physiotherapy is the only thing that did any good but I can't go because of lack of transport'.

255 'Over the years I have had one or two bursts of physiotherapy, I do it on my own I have a static bike which I peddle with my hands and feet'.

256 'I did have physiotherapy at Princess Alexandra hospital for a while, but they just stopped it without discussion. The ambulance wouldn't take my wheelchair. I was given a few exercises to do at home, but found it difficult due to lack of space, I would like physiotherapy at home, because of my spasms I would not like anyone else (but my husband) to collect me to take me to me to physiotherapy'.

257 'I had lot of physiotherapy in Homerton hospital immediately following my stroke but it was not a stroke ward most people had had accidents, they told me they couldn't do much for me. Then I had a lady once a fortnight at home, it was better than nothing, but I would have liked it more often.

258 'I had physiotherapy at school, when I left school I had an active job so I didn't feel I needed physiotherapy. Then I was made redundant and sat around a lot now I realise that was bad for me I should have had physiotherapy again. My GP didn't suggest activity, I have only had physiotherapy in Pine since'.

Some people have had physiotherapy whilst staying at the Pine Unit:

259 'I no longer get physiotherapy in Pine. I got together with other patients and wrote to the Consultant about the lack of physiotherapy, we had a little bit, went in the pool twice, I liked the sensation of standing up, I was not told why I went in the pool I was not told why it stopped'.

260 'I used to get physiotherapy in Pine, at first it was twice a day, but the physiotherapist has no time for us now. It used to be on Pine Unit but it is elsewhere now and often there is no porter to take us'.

261 'I don't get much physiotherapy now when go to Pine. The Doctor at Harlow says I still need physiotherapy but it was stopped'.

262 I used to have physiotherapy on Pine, it was good, but now I don't have it I was told I was too old, and when I was dizzy and fell the physiotherapist told me I was putting it on'.

263 'Physiotherapy at Pine is not as good as it used to be, we used to get longer, now they are too busy for us. I had it at Princess Alexandra hospital one day a week for a few weeks, then they stopped it. I feel it does me good, I would like to have it on a regular basis'.

264 'I used to have physiotherapy when I went to Pine but not for the last six months, I was told there was nothing they could do for me, but it made me feel that someone cared and was interested it gave me hope, I miss the exercise'.

265 'I get physiotherapy in Pine, it makes me feel better, they give me exercises for home, but I need a firm surface and I've only got the floor, if I get down there I can't get up'.

266 'My husband used to get it in Pine, it is no good to him now. When he first had his stroke he went once a week for a year, he even went back driving. After the second stroke he had a bit more therapy for a little while then his sight went, they said they couldn't do any more, then two years ago he had another stroke'.

Comments from people who live at Chigwell House:

267 'I've not had physiotherapy since I came to Chigwell, I don't know if would do any good'.

268 'I don't get any, I've been waiting five years for hydrotherapy and I am supposed to go to physiotherapy once a week'.

269 'I should have it but I don't, the physiotherapy service has always been terrible. I should have it three times a week, it would make me feel more comfortable'.

270 'I used to go two to three times a week but I've not been since I've been in Chigwell. I need it badly my body is getting stiff. I have asked for it but I was told I don't need it. I have a bad shoulder it gets too painful to move, I would like a masseur they all know I suffers I have asked but nothing happens'.

271 'There is physiotherapy here, I have asked for it but am told it is fully booked'.

272 'I used to have it twice a week, I still do a bit of basket ball and keep fit. I used to have callipers but they got too heavy for me but I could walk, I would have liked proper boots not calliper boots, I would love to stand and walk, I wish I had never gone into wheelchair'.

7.5.9 Speech therapy

273 'I never knew about speech therapy until three years ago until a speech therapist came to the Parkinsons disease club. After that I had it every day for two weeks in a group of four. I also had it once a month for a while, at St Margarets. I have been given exercises to do at home I was told I could have more if I wanted it, but she left Christmas '90 and I have not

heard from them since. I have asked various doctors about more speech therapy but I have been told that at Harlow (Princess Alexandra hospital) there is not a room that is suitably equipped'.

274 'My husband has not had speech therapy despite the fact that he can not make himself understood at all and writes everything down'.

275 'I had good speech therapy while in hospital, then when I came home I went to St Margrets but it was changed to a large class and I felt I needed individual treatment, I couldn't cope in a group so I was told not to bother going'.

276 'I have been offered it but I don't feel I need it'.

277 'My wife has it periodically, we can 'phone if she's wanted. She gave us a Possum which she uses with a special switch and also advised on diet, drinking, straws etc'.

278 One man despite his inability to speak clearly due to a stroke does not have (and does not think he has ever had) speech therapy.

7.6 Respite Care

Some found the stay in Pine enjoyable and beneficial:

279 'I have respite care in Pine for two weeks every couple of months, I enjoy it, I have nothing but praise for the staff, I get plenty of physiotherapy, I enjoy occupational therapy (making stools, toys etc.). It gives my wife a break. I know at the end of each visit when my next one is so that we (the family) can plan for it. The only drawback is not being able to be with my family properly'.

280 'Going to Pine is good, it gives my husband a break, I can have a bath, get my hair washed and company'.

281 'I go to give my husband a break, I have made friends in Pine, I am satisfied with the treatment'.

282 'I have been in half a dozen times when mum is in hospital, I don't mind it gives us both a break, it gets me out of bed, I laze about a lot at home, also I go to physiotherapy every day which I like'.

283 'I have been going for three years I don't dislike it, I get physiotherapy every day, it gives my wife a break'.

284 'It is very good going into Pine, I have been going for three years, my Consultant recommended it. I like going in, I have made a Christmas cake and mince pies, been taken out for the day, and taken part in quizzes, I go into Epping with the nurses, am active in the garden, at jumble sales etc. I am happy there, I get on well with the staff, I am stimulated. But they have been bringing in bank nurses recently who know nothing about us, they are not very good'.

285 'It is a godsend, I meet other patients, and have a friend in that area who can visit me in Pine but not when I am at home. My husband looks forward to it, but we would like to know when it was going to be so he could plan a holiday'.

However, the majority are not happy with various aspects about Pine:

286 'I went in to give my husband a break but I got depressed and won't go again. I only got ten minutes physiotherapy per day. My husband didn't really get a break he still came to visit me because I got depressed. I don't like to be away from home I didn't like the treatment/attitude of the staff, they complained at having to turn me at night. I think the idea is good if it was set up better. Each of us phoned to cancel the last visit (ie 2 phone calls) the ambulance still turned up. We feel angry about the lack of continuity and waste of money. '.

287 'At first I used to go to Pine about every eight weeks, then the gaps between got longer. I went in the first place because my husband had two accidents at work because he was tired and couldn't concentrate. So I went in to give him a rest. He can't sleep through the night because he has to turn me. It would have helped if he could have had a rest before the accident. He really appreciates the rest and the first visit was ok for me, but I have not enjoyed subsequent visits, I feel I come out in a worse state, though he has rested he has to work harder when I come back because I feel worse. I don't feel I get any benefit, there is not enough physiotherapy, the food is cold, often they have no pads for her, I have to take my own pads and my own tablets. The toilets are dirty, there is a lack of blankets, I don't like to disturb staff in the night to turn me. After one accident when he hurt his back he was shown the correct way to lift me, he has not had any further trouble, but it would have helped to have been shown earlier'.

288 'I heard about Pine through my GP, I had just gone into a wheelchair and was invited to go for a look, I liked what she saw, also my husband got a break and I got more physiotherapy. Now I feel that it is not worth going to because there is no physiotherapy and I have problems using the toilet. It is a good idea to give the carer a break, but I don't like it, I prefer to be at home'.

289 'I tried Pine, but it was no good, I was not offered any physiotherapy. It was not a break for my wife because of the difficult journey she has to visit me'.

290 'I don't love it but I go because it does my husband good to have a break'.

291 'I had hernias lifting my wife, she was put in psychiatric unit for elderly people (only in her late 40's), it was a very poor standard of care, very undignified, so even though I was still ill I brought her home. The nurses were visiting to bath her at that time, I think we found out about Pine through them. We don't like Pine, it is a very lacking place, the staff are always in the staff room, smoking, drinking coffee, never near the day room, there is a lack of care and concern. She has been a couple of dozen times, I still go in to feed my wife, but at least I get a good nights sleep. She doesn't like going, we have no confidence in the staff, but in order for me to be able to carry on at all I put her in there. She has also been to the Multiple Sclerosis society rest home, the Multiple Sclerosis society paid for it, we found out about it through the local Multiple Sclerosis group. It is a lovely place very caring, why can't Pine be like that?'

292 'I didn't like Pine, there are depressing cases, it upset me. I tried it twice but I can't go again. There is a lack of concern on the part of the staff, for example they didn't cut up my food, my husband spent more time visiting me in Pine than at home. The idea is ok, but it has deteriorated, it would be ideal if you could go for a day, if it was more flexible'.

293 'My husband goes for one week every five to six weeks, my GP wrote a personal letter to the consultant for my husband to go. I said no at first because I wasn't sure what it was about, they put it 'you need a break', they didn't go into details. After it had been explained I made terms as to how my husband should be looked after, I am afraid of how they might treat him, a loss of dignity etc, I still worry about him going in case he doesn't get attention. At least I gets a full night sleep though I go to visit him every day'.

294 'There is no support, no break, no back up. We found out about Pine through our GP, it is to give my wife a rest. I don't like hospitals full stop, I just sat and watched television when I was there I hated it. You are in with geriatrics not with people with similar disabilities. I was told I'd be grouped with people with same sort of disability, that they would organise outings, that we would have physiotherapy, and flexible meals. At first it was not quite like a hospital, I had a single room , took my tv, the physiotherapy was good. As a bribe (to go) I was told I can only have steroids in hospital they put weight on but physiotherapy takes it off. The staff were normally brilliant, at first there were always six to seven staff about, but recently there were no staff to be seen, my wife had to stop a patient choking because there were no staff about. The last time I was told I'd been put in shared room with someone who shouts, I was angry and upset, complained and came home. I was not allowed back after that'.

295 'I went to Pine to give my mum to a rest but I didn't benefit. The staff are alright the standard of care good, you are well looked after, but it's not like a home environment, it is institutionalised. The idea of Pine is fine and essential but the setting is wrong'.

296 'There is no guarantee what date he will be going in so I can't plan anything. The staff sit in a little room and take no notice when he wants to go to the toilet, when I visit he is wet, I do his washing when he's in Pine but they still take it and loose it, it is expensive and I see others wearing his clothes, it annoys me. I have tried to get him in at Honey lane for respite or at the day centre, but they say no he's too young, I don't see that it matters, he's had a stroke, it would have been handy for me, I can't go to see him at the weekend when he's in Pine - I can't get there, also he'd be able to have a bath'.

297 'I went in the first time because my wife was in hospital, it was a crisis, there was no alternative. Though all my family is within ten minutes of me they can't be there to look after me full time because they are at work and have their own families.

7. 7 Transport

7.7.1 Car

298 'I have my own car but I have transfer problems'.

299 'I can't get in the car because of spasms, my wife can't help, it is a problem it means that we can't go out together, we do get mobility allowance but it doesn't go anywhere near changing the car.'

300 'I go out in my brother's car. We found out about the swing out seat that we bought. My friends also transport me, I use several so that I don't abuse them'.

301 'I have my own car, I found out about motabilty through ARMS, I haven't had any training about transferring into and out of the car, but Social Services did give us a sliding board'.

302 'I bought our car with my wife in mind, I used my common sense, I didn't know of any literature'.

303 'We don't have a car at present, my partner can't drive, she did but is now taking lessons in an adapted car to use mobility allowance for car'.

304 'We have our own car under the motability scheme, it is adequate and covers our needs, but we found out about it by accident, we feel that someone should tell you of your rights, we have been able to buy a more suitable car'.

305 'We have our own car bought with my wife's disability in mind, we got literature about cars and mobility allowance from the social worker, but the wheelchair is heavy for me to dismantle and stow in car etc'.

306 'We had to get a bigger car, an estate, when I was ill. I get mobility allowance, we found out about it from television and checked with the nurse who said we should be able to get it'.

307 'We have our own van type vehicle, we got information on different types of vehicles, the garages brought them round so I could "test passenger" them, I am easily travel sick due to my illness, this one had the seats taken out and a wheelchair lift installed'.

308 'I used to have my own car, it was my choice, I was not given any advice on what sort of car, I had an assessment for driving at BSM and all hand controls fitted, the cost at that time £500 for adaptations. They took all my mobility allowance, therefore there was no mobility allowance for for insurance (heafty) or petrol, but I saved up out of my other benefits because a car meant so much to me for my independence, I was just like anyone else, I could go where I liked, when I liked, take friends out. But under the mobility scheme you are only allowed a car for three years then you have to have another and pay for the adaptations all over again even though the present car is still fine. I was not allowed to buy it, I can no longer afford to pay for the adaptations (over the three years I saved up from the other allowances the money for the adaptations), but it is now £1500 and I can't afford it so I don't have a car any more. I tried taking it up with Social Services but they said the car was a luxury, I said it was my only way of being independent. I tried getting money through charities to help with rental, but no luck so now I have got my mobility book back and my allowance and have put a deposit on an electric wheelchair but I will not be as independent as when I had a car'.

309 'We have our own car, but transferring her is difficult, we would have liked one we could push the wheelchair into but we can't afford it. Lateral support for her in the car is difficult, information on choosing cars would have been helpful because we feel we have made mistakes in car choice. The mobility allowance goes nowhere, it is a nightmare claiming the VAT back'.

310 'We had a car through motability, we are fully dependent on it, but another car smashed into it, we asked for a loan car while it was mended they said no. We found out about motability through a friend, our GP had never heard of it. We had no advice on the choice of car it would have been useful with us both in wheelchairs'.

311 'I have a van that I drive into the of. I have to rely on others to drive me'.

312 'Mum and dad have got a car but they are out in the day. The car is ok it has a ramp, so I can go in the back in my wheelchair'.

313 'My mum had her own car, but she can't drive anymore'.

314 'I've got my own vehicle my wheelchair goes in the back but I need a driver, my mum is too ill now to push me up and down the ramp, I need a new assessment'.

315 'I don't have any private transport I have to rely on my son therefore we rarely go out'.

316 There is no transport for me at all, the taxi drivers only take me because they know I am. There is one black taxi but it is not made well known. My mum does the driving but transfer in and out of the car is difficult. We've not had any advice from the occupational Therapist and I fall between the car and the wheelchair'.

7.7.2 Public transport

Buses

317 'It is half a mile to the nearest bus stop I can't walk that far and I wouldn't be able to get on and off'.

318 'I would like to use public transport. There are little buses that run round the estate every ten minutes few people use them, but if they could convert two to take wheelchairs, I think that they would be full because there are 5,000 disabled people in Harlow. I wrote to the council and the local paper about it'.

Trains

319 I can get a train from Stanstead or Chelmsford to Liverpool St and get a friend to meet me or travel round London on the disabled bus service or use the new London taxis'.

320 'It would be wonderful if the underground was like Newcastle Metro and its free for disabled people'.

7.7.3 Taxis

321 'They are expensive, there are no tokens or cards'.

322 'The taxi drivers are very helpful, they lift my wheelchair in, my mobility allowance pays for using them'.

323 'I have a good taxi driver, he doesn't have a special adapted taxi he puts my electric chair in the boot and lifts me in, I've used him for two years I always 'phone up and ask for him'.

324 They are alright, when I phone I tell them I'm in a wheelchair, there are no concessions'.

325 'I don't know of any adapted taxis'.

326 'We don't even have taxis where we live'.

327 'They won't pick up people in wheelchairs'.

328 'If they had one adapted for a wheelchair I would use it'.

329 'I can't use one because I can't get out of my chair'.

330 'They've got one adapted car in Harlow, I tried it, it was good but I had to pay more. I wish we had a token system so we could have cheaper taxis'.

331 'I use adapted taxis, I pay the full fare, the taxi driver is really helpful, but I feel non-disabled people are abusing it, ie those with push wheelchairs and those who can walk, it is only for those with electric chairs'.

332 'It is a problem at Chigwell you have to use taxis even if you are only going to the village, they are expensive, different firms charge different rates for the same destination, some add more for carrying a wheelchair'.

7.7.4 Driving lessons/retraining

333 'Before I was ill I was up to test standard I was going to continue to drive and had hand controls fitted but the instructor sexually harassed me, he frightened me, but there was nothing I could say, it was my word against him. Anyway there is nowhere for me to park at this flat to transfer in from my wheelchair'.

334 'I would need a converted car before I could learn, even with our combined mobility allowance we couldn't afford a vehicle and wouldn't have any left for insurance, petrol etc, paying for lessons would be a problem'.

7.7.5 Dial a Ride, etc

335 'It would be good for a day out occasionally or to go shopping somewhere else, like Romford'.

336 'I would be good I could do what I wanted when I wanted to'.

337 'I had an interview a few years ago they said they might get one going through the local council, it would be useful I would be able to take my husband shopping with me'.

338 is a movement for 'dial a cab' and a 'taxi card' system there has been representation to the council by a firm willing to do it in the area and the council are considering it. It is long overdue, they also tried to get dial a ride but it was shelved because of the 'dead milage' because it is a rural area'.

7.8 Education

339 'I would be happy to try any new skills or follow up existing ones for example like I do in occupational therapy in Pine'.

340 'I would like to learn VDU skills'.

341 'I would like to learn computing but I think my eyesight is a problem.'

Responses form people who live at Chigwell House

342 'I would like to go to college to do art, but transport is a problem and I don't think I could book the disabled taxi on a regular basis because there is only one'.

343 'I was doing art but transport and class size were a problem and my memory for learning other things now'.

344 'I went to Loughton college to do A level art'.

345 'I left school twelve years ago and took O levels now there is a possibly of going back to college in September to study A levels'.

346 'I have been doing computing and pottery at Chigwell but to do it elsewhere transport would be a problem'.

347 'I go to Loughton college one day week for; computing, discussions, maths, I enjoy it I feel it is worthwhile and make friends'.

348 'I do typing and word processing in the training centre, I would like to go to college'.

349 'I have done a two year catering course, I'd like to do car mechanics and cooking'.

350 'I used to do pottery, I would still like to. I would like to do an evening class. I go to college every Thursday but the office staff told me they don't think I should go any more it's not doing me any good, but I want to go and mix with other people so I'm not with the other residents all the time. I do computers, maths, English, money, I enjoy it immensely. I go to Treetops (training centre) for the programme. I didn't help plan it, it is not designed for me, they decide for me, I just go to get away from four walls, but it is not very good'.

351 'They wouldn't have me at school with my sister because of my handicap. I had to live away from home. I finished at 16 (only in early 20's) and have not had any further education or training. I would have liked to have done A levels but they didn't think I needed it. I would like to go to college but I would need to check about the toilets, I'd like to do painting and English, etc, just basic things. They know at Chigwell that we are keen but nothing is organised'.

352 'I do psychology at college I arranged it myself even where to find the money. I needed a grant because I needed a facilitator because I use a wheelchair and am blind. I wrote to trusts and got money. I pay a facilitator £5 an hour, I advertised in the college. I also go to an access course at the local college once a week they look at what you can do from an academic angle what can't do and what you want to do, they facilitate learning and integrate you into the college'.

353 'Courses are expensive I wouldn't be able to afford to pay also transport is a problem'.

354 'I was told that I had to strictly adhere to the training programme which irritated me because it was not relevant to me, I had been working prior to my spinal injury'.

7.9 Employment

355 'I was never classed as disabled at school until I was leaving and they said the job I wanted to do I couldn't because of my disability and I was given a list of jobs they thought were suitable for disabled people. I was shocked, I had not thought of myself as disabled before that, so I just went to work in a factory. That was ok, I was active, it kept my strength up, but when it closed down I was made redundant. I have had only occasional work since, I am registered unemployed and willing to work, but I'm not bothered about it, it would be difficult because of the weakness in my arms'.

356 'I attended a special school and I went for an assessment at a residential centre though neither training nor work was suggested. Somehow I ended up at Chigwell, I learn a lot more than at school, I have been happy here but now I feel I have finished this stage and am ready to move on, I want to go to residential place where can do art but it is a long wait'.

357 'Work would be out of the question but I go to Chigwell. The warden on the estate suggested it, it has been very very good coming here it has let me get out and speak for myself I let others talk for me before and I she sat back. I hadn't done anything since leaving school and coming here (30 or so years), now I've learnt to cook, I'm interested in the computer, I do a bit of pottery, I am a different person altogether'.

358 'I did YTS after school, the DRO suggested that I went to St Loys training school where I did telephony and typing and passed but I didn't bother trying hard to find work. I am happy

not working. I finished there came home and that was how I come to Chigwell one day a week for rehabilitation'.

359 'I set up a charity in 1975 called "Handicapped on holiday abroad". It takes up a lot of my time fund raising and organising. I also go to Chigwell for Rehabilitation, I have found it very beneficial, I have found out a lot of things'.

360 'I am teaching but I couldn't move if I wanted to because I have been given so much help'.

361 'I would like to go out to work, I feel in a rut, I want to see more people'.

362 'I helped out at a nursery which I loved, but it stopped because of transport'.

363 'It has not been suggested to me that I could train to do work'.

364 'I would like to work with children, I have raised it here (Chigwell) but no one has taken it up, it has not gone any further'.

365 'I would like to be in catering or to work with cars'.

366 'I would like to work with children, I have done it voluntarily, but if I did I would loose my benefits'.

367 'I have never thought about work, nobody has ever talked to me about it. I like typing, nobody has had time to explain what things I could do'.

368 'I would love to work but I would need to find somewhere else to live because if I earned more than £6 a week I would have to pay to live here but I am over 40 and we are in a recession so I must be realistic'.

369 'I had a job, I worked for the Gas Board as a trainee clerical worker, it was great and I had a social life. They spent money on making toilets and fire exits etc. accessible for me, I was covering a woman on maternity leave and she'd said she wouldn't come back. I thought I'd got a job for life, but she came back. I worked there for nearly a year that was two years ago. I've done employment and training clerical course, I enjoy clerical work, I keep applying for jobs. It it has affected me I get depressed because I haven't got a job. I have never seen a DRO while I've been at Chigwell, I saw one in Colchester but I got the job with the Gas Board off my own back. I would like to do work on a voluntary basis just for the experience and pocket money'.

370 'I haven't got transport to get anywhere also I am not registered disabled because I have not been declared as disabled because I wasn't born disabled. The employment place hasn't got a DRO, but if I was found fit for work how would I get there, I can't even sign on because I can't get there, I have to prove I'm ready for work but how when there is no transport. I

can't afford to go for interviews. I would prefer my job to be looking after my wife to be but they wont pay me to look after her though it would cost them more for her to be in care'.

7.10 Leisure

371 'I used to swim at Princess Alexandra hospital but it was stopped I think the pool is full of equipment now. There is a pool in Harlow but I think the water might be too cold, though they heat it on a Saturday morning for senior citizens, so it could be heated for people like me'.

372 'I would like to go swimming, there is an accessible pool and a disabled club but for mentally handicapped people, I would go with others who had Multiple Sclerosis but not with those with a mental handicap'.

373 'I Would like to go swimming but the local pool is not accessible, the water is too cold, the children's pool is a nice temperature, but how would I get into it?'

374 'There is disabled swimming here but it is at night which is no good because of my little boy it would be better to be able to go in the day'.

375 'I used to enjoy swimming but they don't go anymore unfortunately there are not enough staff. I would like to go to watch sport, I would like to have a go at dry slope skiing in the special thing they've got for disabled people'.

376 'I would like to go swimming, my key worker used to take me, she offered to but the office put a stop to it. I had to go in taxi which was £7 plus the cost of the swim that was all my week's money gone, but it was the only kind of exercise I got'.

377 'I used to go swimming but I've not been for 10 years it helped my legs. They know (staff at Chigwell) we want to swim, but I need a costume, other people go and I didn't know for ages that they went they don't tell you if you don't ask'.

378 'I have bird tables outside my room and like to watch the birds. I used to have a budgie, I am hoping to get another but the person in charge is not happy about it though it says in the prospectus that I can. I do a little sewing, embroidery, knitting, make jumpers, read, I am in a gardening group, I've been to a flower show and exhibited the things we grew'.

7.11 Social activities

379 'I can only go out with my husband, only he can cope with my spasms and I only trust him and feel confident in him, but we do go out for meals, to an accessible theatre, visit family and friends, goes shopping with my husband'.

380 'On the whole my social life is not affected, but access to restaurants etc is a problem, I have to ask and check first (once I went to a disabled toilet up five flights of stairs)'.

381 'Weather permitting I have a scooter and can do my own shopping, I go to bingo, I am quite happy with my social life, I am the social secretary of the Multiple Sclerosis Society group I arrange outings and events for that, I don't mind my own company but I always have people dropping in'.

382 'I do visit friends but only when my wife can take me, if I could get transport I could visit them on my own'.

383 'I don't like being reliant on people to take me places, I would like to be able to use Dial a Ride, but I'm not in the catchment area, taxis are two expensive, I.would like to be more independent'.

384 'I would like to go to the pictures, theatre, etc but my night nurses come too early, I don't like the idea of going to matinees, I want to be the same as everyone else. The old cinema in Harlow is not accessible, I was told that I was a fire risk, the new cinema is accessible but though it is not far you need a car to get there because it is in the middle of a big roundabout'.

385 'I would like to go shopping but toilets are a problem'.

386 'We used to have a very active social life, but it is such hard work now; transport, accessibility, lifting the wheelchair in and out of car'.

387 'I would very much like a more active social life for stimulation, but it is too daunting to try'.

388 'I can't go out, no car and transfer and toilets are a problem, I went out on the Multiple Sclerosis bus shopping once, but it was too uncomfortable'.

389 'I like to go to the pub, I used to be in the darts team and won trophies, but now I've lost the strength in my arms and I can't stand, I would like to go to the cinema, but I have been told I am a fire risk, I used to go to night clubs ect in the '70's, but I think the law changed in the '80's that says I'm a fire risk and I am no longer admitted'.

390 'I am very busy on committees, Women's Institute and a music club, I am in and out of the house, it is nice to have activities with non disabled people. There is a place in Epping called Centre Point they have many things for able bodied people but nothing for disabled people or for disabled and able bodied people to mix for example, a PHAB Club'.

391 'I go shopping with mum and dad, I go to the pub, I would like to go to the sports centre for bowls etc, I have been to concerts, I would like to do more, but transport is a problem'.

392 'The big problem is transport, I amuse myself indoors but it would be nice to get out if I had transport, mum had a car had but had to give it up because of illness, I would like to go to the theatre, social clubs, etc'.

393 'Because of lack of transport I can't go anywhere except the pub across the road'.

Responses from people who live at Chigwell House:

394 'I would like to go horse riding and to watch horse racing. I like going shopping, I sometimes go with staff when I buy clothes. I go every Monday fortnight to a club where we play bingo'.

395 'You can go shopping with your keyworker but I have never been with mine (in 2 years) I go shopping when I go home. I go to a PHAB youth club twice a week, I love that I've made loads of friends, I love discos and cinema, I don't know if there is a cinema round here so I've not asked'.

396 'I go to the PHAB club twice a week pub, the pictures, football matches, train spotting and play pool and snooker and watch television'.

397 'I go to a club twice a week, a disco, but I only have £10 a week to buy all my toiletries, to pay for transport and for social activities, to save for presents and a holiday, I am also trying to save to buy things for my own flat, so I can't do much socially'.

398 'I am happy with my social life, I go to the pub and restaurant'.

399 'Occasionally I go shopping, I go when I want and get what I want and use the taxis. I would like to go out more, I hardly ever go out. I go to college and occasionally on a Tuesday evening. I belong to a stamp club. I would like to go to concerts, films and theatre. I would like to do things outside Chigwell and start a relationship. The PHAB club is boring'.

400 'I go to the PHAB club when there is a Chigwell bus or go in a taxi. I have got to know more people and to socialise, I like discos. I like the pictures, sometimes I go with a member of staff if there is one free'.

401 'I like to go shopping, I would like to go more often. I go to a luncheon club at church once a week, I would like to go to the cinema but they are not accessible'.

402 'Social activities are very difficult because lack of transport means I can't get there'.

403 'I've never been to a pop concert, I would like to'.

404 'I go to pub or out for a meal now and again, I am happy with my social life'.

405 'You can do what you want but it comes down to your own personal finances, I am happy with my social life though it was better when I was working'.

406 'I don't go out because it is too expensive, I only get £10 a week and transport is expensive. I can't afford to go to the pictures. We used to invite an officer to go with us and use their car to go to the pictures but because of the contract in the flat we can't do that now. We don't see any possibility of a social life in our new home because of lack of money, transport etc. We are not staying in people we like to get out'.

Day centres

407 'I would like to go out but the day centre is full of old people, I don't want to be lumped as one it is bad enough being disabled'.

408 'The secretary at my GP's asked me if I'd like to go to a day centre for elderly people, I am taken two days a week from 10 to 3 ish, I have a cup of tea, chat, take my lunch, do a bit of knitting, but they are mostly older people and not much company'.

409 'I am going to start going to a day centre, I am not looking forward to it, I like to be at home, but my husband needs a break'.

410 'I go to the Barnmead Centre three days a week, Social Services told me about it, I have been going for three years, I am collected, I do handicrafts and it is a chance to socialise, it is satisfactory'.

411 'I go to the Lea Manning Day Centre two days a week, 10 to 3, but I do nothing more than sit and chat, there is an art club, they do a bit of knitting and sewing, but I can't, I would like to go more often but the waiting list and transport is a problem, there is no local transport, they run their own transport. I would like to go to the theatre, cinema etc, but I have no transport'.

412 'There is a day centre locally I might like to attend but I think you have to be 65'.

413 'We both go to a luncheon club once a week in the community centre we go in their adapted van with lift'.

414 'My sister who works at an old people's home arranged for me to go to the day centre at Barnmead but they are all old people and I didn't want to be lumped in with them'.

415 'I would go to a day centre but age is a factor, everyone is older and it is depressing I want to integrate'.

416 'I like the idea of going out for a day, if I could have lunch, keep fit, yoga, physiotherapy, but transport and the toilet is a problem'.

417 'I go to a day centre two days a week, I have physiotherapy one day it is a trained physiotherapist who does it voluntarily, the methods change with individuals, each time it changes I have had better treatment. I am now using a standing frame for half an hour each day and feel much better'. (from a man in his early 50's who had a severe stroke a number of years ago)

418 'I go to a day centre they collect me in their own minibus with tail lift, I have physiotherapy and local companies ask for things, eg printing, photoframes, contract work, packing, gardening etc, but it is under threat from council cuts, we also do things like have a pub lunch, go to the seaside, have evening meetings, I get a lot of information there that I would not have known otherwise, we can share ideas and support each other'.

419 'I like the idea of a volunteer visitor, but I don't know that I would feel safe, what if I didn't like that person how could I get rid of them?

420 'Crossroads visit twice a week for two hours, it is not enough, we don't manage a social life other than going to the pub regularly with a group of friends'.

421 'I would like more chance of a break, but appreciate that we get a lot of help and it is not possible since all these people work as a team. A lady comes from Crossroads 9.30 to 4.30 once a week so I can get away for a day, they offered if there is any time we want her for an odd hour they will do it'.

422 I have Crossroads ladies to sit three mornings a week so I can go shopping or just have a walk to calm down, they are flexible'.

423 'Crossroads visit on a flexible basis if my husband has to go out, they have been visiting a long time, my GP told us about it, I declined at first, but my husband needed a break so have it, I don't like being alone in the house with a stranger, but if I am alone I worry, I can't move, I worry that someone is trying to get in'.

424 'Crossroads come on a Friday afternoon, we had one a long time ago then after 12 months they stopped coming, they only recently started again, it would be nice if I could go to work and know someone was there to care for my my wife, Crossroads is not flexible enough'.

425 'Crossroads visit, they are flexible and only come when I need them, for example when my brother is out, I found out about them through the disabled group, they come to make me a drink or a meal if I am ill in bed or if my brother has to go out for the whole day'.

426 'I enjoyed the Women's Institute and the over 60's club but I can't get there now'.

6.12 Religious activities

427 'We are very disappointed in people's attitudes because we had been very active in the church until my wife had Multiple Sclerosis:

428 'It was very important at one time, but we are disappointed in the attitude of the people we met there, the hypocrisy when we needed help, therefore we no longer have any contact and we worship in our own way'.

429 'It is very important, but we don't go to church because of access and discomfort, we are not interested in church people coming'.

430 'I am taken to church and Sunday school, I enjoy people's and children's company, it is important to me, the vicar used to come, I would like to take more part in something to do with church I would like to visit sick and old people'.

7.13 Holidays

431 'I miss going abroad, I feel I can't with my urinary problems and the pads and things I would have to take with me, but I would still like to go'.

432 'I feel too ill to go on holiday, it is too fatiguing for me to travel, my wife misses the break, but who would look after me if she went, or if I went who would push me round?'

433 'We have stayed with relatives until recently but it is getting more difficult because their homes are not adapted, she has been on holiday to an adapted place with the Multiple Sclerosis society but I (husband) would not like to do that with her I need a break from disability'.

434 'We don't have holidays,we have financial difficulties and there is the difficulty of arranging it and my travel sickness and visual problem'.

435 'We did manage holidays until fairly recently, but now I am on a special bed, I used to take my spenco mattress and go with my husband and son because I needed help with lifting etc, we booked disabled accommodation but it is still not always accessible, but now holidays are not possible'.

436 'The whole idea of organising one seems too overwhelming, organising the transport, and finding somewhere accessible. I don't want to be with lot of other disabled people. It would

make me feel selfish if I went away for a break while she in Pine, also there is the difficulty of affording it'.

437 'When I had a car I could just go with friends, we'd have a caravan and be totally independent, my disability was not an issue, but now I have no car I can't go, I miss it, I used to take my neighbour who has lost wife, so we both miss out'.

438 'We have not been for a couple of years because of the heights of beds and the lack of handrails. The DSS gave us a list of holiday places to go without us asking, but last time we went I was glad to get home, but I miss holidays'.

439 'It would be no holiday for my wife to go on holiday with me, I am trying to persuade her to go while I am in Pine but she feels guilty. I wouldn't want to go to disability places because they would be depressing, but then there would be difficulties of using the toilet and getting in and out of bed'.

440 'We have not been able to have a holiday for 6 years, I was sent 35 brochures by the organiser of Crossroads but not one would take me because of my epileptic fits, it makes me feel dreadful as if I am condemned, also transport is a problem'.

441 'We have tried, I really wanted to go away, we saved up, people put brochures out for disabled but they don't cater for us at all, we can't get into hotels, the disabled sign is broadly used and is very misleading, we were given a chance to go on holiday with the social club the nurses were all sorted out, when we got there it was not accessible, I was trapped in my room and it was so difficult to get in and out of'.

442 'I went to Spain through the Spinal Injury Association but it was a struggle, I went on two disabled holidays in this country and hated it, going on holiday is more of a problem than a benefit, hotels often say they are accessible but they are not for people who can't use their hands'.

443 'I went with my family, we had no problems getting information, we went to Centre Parks in Nottingham, everything was accessible enough, we all had a good time'.

444 'I went on holiday with my partner to an adapted hotel, British Rail were very good, the hotel was OK we found out about it through the Multiple Sclerosis society, they also booked train etc for us'.

445 'I go with my husband and friends to an adapted flat, my husband has been on holiday while I have been in Pine'.

446 Mobility is a problem, I have been to the States three times, each time it gets more difficult, we go as a family so we can all can help each other, America has good facilities'.

447 'We go with another couple where the man is in a wheelchair, we hire a van with a tail gate and driver he takes us to Cornwall and Scotland, access is good, motorway services access is good, it is expensive but good'.

448 'We visit a friend in Holland, everything is all accessible there and the boat is accessible'.

449 We go with all the family so we can take turns at looking after my husband to give me a break, I have been abroad with my children'.

450 'I've been every year for twelve years with a friend, we go for two weeks, we find a hotel with rooms on the ground floor and a lift, we have gone through the RADAR books, they leave a lot to be desired, people talk about accessibility but they don't always do it'.

451 'I go with my mum and dad mostly in this country, it is ok, hotels say they are accessible but often they are not, I've not heard of RADAR booklets etc.'.

452 'I go with my mates to Florida, Cyprus, Newcastle it is easy to make arrangements, America is no problem, I could go on my own but with a friend it is more accessible'.

453 'I went to America it has very good access and they treat you as normal. I went with my sister, aunty and mum who all had to go to look after me. We booked it through the travel agents, we explained about my disability but we still ended up with problems. The travel agents need training, because I was flying to America the airlines said I had to have a catheter in, I can't use a catheter, How do we find out about holidays when we don't want to go with other disabled people? I would like to go on activity holidays with ablebodied people without my mum'. They had not heard about the RADAR holiday book.

454 'My family took me to America they all share/take it in turns looking after me'.

455 I have been restricted going with my mother and father I could go on group holidays but the age group is a problem I have had a RADAR book but haven't used it, I want to go with people who are not disabled, I lack the company of my contemporaries'.

456 'We use general brochures and look for things that may be suitable and the travel agents 'phone the hotels to find out if it is accessible, every time the wheelchair service has been brilliant, we have had holidays in Tenerife, we try to go in February to cheer ourselves up and get through the winter and another later in the year'.

457 'I have been to Florida and I'm going to realise my ambition of going to the Grand Canyon this year. I have confidence in my drugs and have the push chair. For flying I just got a

letter from my GP asking them to put me in a seat near the toilets. I've not had any problems with hotels we just use big chains'.

458 'I have been on holiday with my daughter whilst my wife was in Pine'.

459 'I (wife) go alone for a break, his break is going to Pine, we would go together if we had transport'.

460 'I go on holiday with 'Handicapped Holidays Abroad', I really enjoy it, we have helpers and go to hotels with handicapped toilets and rooms etc. and go in cars rather than ambulances, I've been to; France, Tenerefe, Florida, my mum has a separate holiday'.

461 'I am the organiser of 'Handicapped Holidays Abroad' so I go with them'.

462 'I go to Paris and Scotland, I would like to go on a week somewhere on the end of an aeroplane ride, to go to the sun and not have to do anything just feel rested, a week without hassles, but not in a group'.

Responses Chigwell people who live at Chigwell House:

463 'I go to Hayling Island once a year, I enjoy holidays and would like to go more often and to visit different places'.

464 'I love holidays, I belong to Handicapped Holidays Abroad. My mum found out about it, I don't know anyone else in the group, but it is great'.

465 'Last year I went with a girlfriend and two helpers, but you have to pay for staff'.

466 'You have got to pay for staff to go, I am annoyed about it, but it is the policy. I could go alone. I have been on a Winged Fellowship Holiday, my dad picked up a brochure'.

467 'I am going with a friend and two staff, one to drive and one to help, in a chalet. You have to pay their accommodation expenses, it is difficult to save to pay for both'.

468 'Holidays are a sore point, I don't agree that if you go away you have to pay for staff. It is a recent thing we've not always had to do it, just last year and the three years before. This last time we took an officer and he didn't treat it as if it was our holiday yet we pay for everything'.

469 'I go with ACROSS, an organisation for Catholics. It is really good, I have been to Spain, Rome and the South Tyroll. You are allocated helpers, I didn't know anyone but we all got on,. I also arrange my own holidays in this country, but you have to pay the staff. I need two people to help me because not many places have got hoists etc. You also have to pay

your own transport at 27p per mile, or a voluntary man with a private ambulance service. I have used RADAR but the hotels are not really accessible. I find holidays difficult because of the cost involved'.

470 'They are ok for people who like disabled holidays but I just want to be ordinary and go like everyone else. But I need a carer and you've got to pay for that, I am is responsible for their costs, eg fare, food, etc and my own costs and transport. For example to go to York for a week would be £700 if I used the County vehicle. So I don't have a holiday unless I go with his sister, I went to France in '87'.

471 'It is down to money, I am looking at places for this year, but don't know if it will come off, you need an officer to go with you, I would like to go abroad but I you have to pay for them'.

472 'We went with staff and counted it as our last holiday, we have to pay for staff. I don't know what we will do when we are married and live on our own; how to pay for it, arrange it, etc'. They did not know of any booklets.

7.14 Information

473 'I've had very poor information, I had to go to Harley St to get into hospital to get diagnosed, it took two years for that to happen, they told me I had Multiple Sclerosis with the students around and without my husband, then they told my husband and not me, I was not given any literature'.

474 'I have Multiple Sclerosis and arthritis, it took 2 years to diagnose my Multiple Sclerosis, neither the Consultant nor my GP told me anything about either condition or gave me any contact no etc, I found out about Multiple Sclerosis through a visitor at the library where I used to work'.

475 'Neither in the hospitals or my own GP have given me any explanation of my stroke or any literature, it would have been helpful'.

476 'I more or less diagnosed myself as having Multiple Sclerosis because of talking to other patients, my husband and I were told together and I was happy with that, we looked in the phone book to get leaflets'.

477 'My GP referred me to the hospital the doctor there just said you've got Parkinsons disease take these tablets and I'll see you in three months. I was so shocked, I was only in my late 30's. He made no attempt to explain what it was. So I asked for a second opinion. The consultant I saw that time sent me to the Middlesex and the drugs they gave me brought me back to near normality for a few years. You are left to find out things for yourself. I am

now in the Parkinsons disease society and run the local group. I did need education about the different benefits. When I finally had to give up work I went to the benefit offices and filled in forms. I had never been involved with the Social Services before I had heard they would be unhelpful. When they talked to me they talked in jargon, I didn't know what they were talking about, I didn't know if what they were telling me was right so I couldn't argue my case with them. The woman who visited about the bath seat etc never raised benefits. Information is better than ignorance'.

478 'My wife knew about me having Multiple Sclerosis before me, I heard a rumour that I might have it when I was in hospital, I asked the doctor who just said 'yes', he gave me a contact for the Multiple Sclerosis society and ARMS'.

479 'I was just told I had Multiple Sclerosis, I was not given any explanation, no leaflets, no contact numbers, I just went mad doing keep fit, I thought that if I was fit it would go away, I burnt myself out, now I know I did myself a lot of damage'.

480 'I was diagnosed as having Parkinsons seven years ago, I was just married and seven weeks pregnant, I don't think they explained anything to me, they might have but I was so shocked and upset I wouldn't have been able to take it in, I didn't think of questions until later, it was a colleague at work whose sister in law was a sufferer who told me the address of the society, it would have been helpful to take the panic out of it'.

481 'When I was diagnosed they did not give me any information to help just, 'you've got Multiple Sclerosis join the Multiple Sclerosis society', but no details, no 'phone number'.

482 'I tried the Citizens Advice Bureau about allowances and benefits when I lost some when my partner moved in, I filled in forms but we were blocked, they tried to help but were limited'.

483 'I have not had any financial advice, I got mobility allowance assessed through ARMS, I wouldn't have known where to enquire, I get attendance allowance and Severe Disability Allowance because I had to give up work, but I missed out on twelve months of it, the professionals should tell you'.

484 'I was not given any financial advice, a nurse told me could I could get attendance allowance, I am sure I am getting everything I should be but nobody has told me'.

485 'The hospital didn't register me as disabled, so for ages I didn't know I could get mobility allowance, attendance allowance and severe disability allowance, I didn't know you had to be registered'.

486 'The social worker has just told us about the Independent Living Fund, you can get money and employ people to look after you, but how do I (with my disability) advertise and

interview people, I need qualified people or I will not feel confident, what about paying their National Insurance and what about holiday cover etc? I'm not up to it, they would pay 91 hours at £4.80 per hour, how am I going to get qualified people for that? When my husband works (which is not often because he has to look after me) he works shifts and weekends how am I going to get someone to work round him? He'd prefer to get that money to stay at home and look after me, he feels he could do a better job, it would cost less, but we're not allowed to because it is open to abuse, I would prefer him to go to work, I think it is good for us both not to be together all time'.

487 'I phone social services but getting through is a problem, trying to find the right person to help you is like trying to find a needle in a haystack'.

488 'I am on supplementary benefit, attendance allowance, full mobility allowance, severe disability pension, invalid care allowance, I pay a reduced poll tax, I have only just found out about the Independent Living Fund, through the Crossroads visitor mentioning it, I have found everything out bit by bit nobody tells you'.

489 'All the information has been forthcoming form the Social Services. Somebody brought or sent some leaflets at an early stage, the Doctor appeared and assessed me, a book appeared in the post, I never had to go anywhere. Once you are involved with the different agencies it all follows on. Various people have asked if I'm getting my allowances'.

490 'I am sure I get all my allowances, the social worker told me about them and I am happy about it'.

491 'I went to the Citizens Advice Bureau to ask about benefits, they told me about them all, I am concerned that when I get to 65 I won't get attendance allowance'.

492 'I found out about allowances from my GP, but we are both paying poll tax, I feel we are not told everything, they don't volunteer information'.

493 'No one told me what my rights are and what I am due to, I went to the benefit place and asked what I could claim they said I couldn't get income support, but I gave up work to look after him, I told them they was wrong and now I get it but I wouldn't have if I hadn't fought'.

494 'I get attendance allowance, mobility allowance and care allowance, a lady at work told me about allowances and I made enquiries'.

495 'No one had asked how we were managing financially, we paid poll tax, for prescriptions, everything and we shouldn't have been, then I was told I would be better off if I didn't

work, we need constant heating because of his condition but there no allowances for that, budgeting is very difficult'.

496 'If I phone Social Services I am asked 'why do you want to speak to a social worker', you are made to feel guilty, I was told it might be three months before they could see me'.

497 'Nobody told me about benefits, I tried to get invalidity benefit, I was told I am too old, I should have claimed at 60 but I didn't know about it, my son got information on benefits, he gets it all'.

498 'Regarding financial advice, I use my own brain, I have used the Citizens Advice Bureau and the benefits shop, I was told I was not allowed income support, then I was told I was we could have been claiming for years, I saw about the Independent Living Fund on the television and took the phone number'.

499 'I found out about benefits through seeing a freephone number in the paper, no one has ever asked what benefits I am getting and made sure I was getting them, I'm still not sure I'm getting all the benefits I'm entitled to. No one has ever discused benefits while I have been at Chigwell for rehabilitation. I have contacted my social worker and asked if I could get severe disablement allowance but he didn't know so I still don't get it' (from a man in his 20's who has been disabled since a child, has attended a special school and a disabled persons training centre).

500 'There is not enough information forth coming if you don't know who to start and ask, we used the Harlow advice bureau about the social fund they were very helpful, the Multiple Sclerosis society has been useful for information but not on benefits. The occupational Therapist advised about attendance allowance, mobility, SDA and income support, housing benefit and no poll tax, we got a grant from the social fund for carpets etc, 90% of our knowledge is what we have learnt ourselves'.

501 'If we know what is available we will take advantage of it the problem is finding out what is available'.

Some people are members of national and local societies.

502 'I go to the Multiple Sclerosis group meetings we talk or have speakers, it is helpful to meet other people with disabilities'.

503 'I used to go to ARMS meetings in Harlow, but it folded, it was full of moaners. Now the nearest group is the Multiple Sclerosis society in Loughton, I can't get that far but also because of my bed time nurses.

504 'I would like to go to Multiple Sclerosis meetings if I had transport and they were interesting'.

505 'I wouldn't like to meet others who are disabled it would upset me'.

506 'I found ARMS very useful, I have been to their centre in London and found about about cutlery and tried hyperbolic treatment I attend their meetings but the Multiple Sclerosis society is not so good'.

507 'I tried the Multiple Sclerosis society I need more information about Multiple Sclerosis, none of their information has been helpful, I would have liked more filling in forms for financial assistance'.

508 We are in the Multiple Sclerosis society, and ARMS. ARMS is more helpful'.

509 'I don't know how but I got involved with ARMS and the Multiple Sclerosis society and used to go to meetings when I was not so ill, I found them useful, I got information, but I got most of my information through the nurse and the home help, I am not sure where the financial advice came from, perhaps Social Services'.

510 'We are Multiple Sclerosis society members, we got literature and have got support recently from them but not in the past, the special mattress came from the society, they even paid for it

511 'I belong to the Alzheimer Disease society it meets once a month, we can exchange advice and professionals talk to us

512 'I have had advice and support from the Multiple Sclerosis society, I got a social worker through the hospital and she gave financial advice'.

513 'We have been lucky with a helpful consultant and nurse, things seem to have flowed, when we needed things they happened, things have been suggested, alternatives have been suggested, we have not had to rummage around for information we have not had to push for things, but you do need to be determined and not sidetracked'.

Responses from people who live at Chigwell House

514 'We have not been given a clue where to go, where to start getting information from, I can't even go to the library, the CAB is upstairs. I don't know of any groups related to my disability that I could belong to (spinal injury). Though we have been on 'the programme' all this time and we are moving into our own home we don't know where to get any information as regards holidays, equipment etc'.

515 'I'm not sure what benefits I get, I pay to live here sometimes. I get spending money, you don't get any financial advice, but I have a bank account. I don't know what other information I want'.

516 'I don't know where my benefits advice came from but I do get allowances. I have heard of the CAB but haven't used it'.

517 'I got leaflets about benefits from the post office'.

518 'I would contact the Social Services or an Occupational Therapist'.

519 'I used the CAB to help me fill in a benefit form'.

7.15 Personal development

520 'We have never been offered any family counselling, regarding our young children it is important and for our parents who don't understand and think we are being lazy. Since we are both disabled we don't need it we can support and understand each other'.

521 'It would have been useful for myself and for my family'.

522 'It would have been useful'.

523 'I think it is very important, it can be more upsetting for the partner, they don't understand and don't know what to do'.

524 'My son and daughter have difficulty coping with this happening to their dad, counselling would help, we are a big family and had lots of friends but now the family has fallen away, they don't understand, they don't visit or offer support'.

525 'It could have helped a lot, it frightened my husband (he left her because of her) he was in the dark, we needed it as a family, I know a lot of people with Multiple Sclerois whose marriages break up through ignorance. My husband was told I had it, I didn't know for two years, I found out when he left me it was very traumatic. I wasn't given any information, I went to the library, I was very much in the dark, I had to learn the hard way. I found out about the Multiple Sclerois society through a taxi driver. You need a doctor or someone to explain things who wont fob you off then you can accept it and plan for your future'.

526 'I would like training so that I know I am doing things correctly for my wife and not making her worse'.

Responses from people who live at Chigwell House

527 'It is not a helpful environment and there is no one to ask. We became more confident and independent through developing our relationship, the staff thought I was a bad influence on

her, we were in trouble. The staff discussed us and made up their minds that we would live together we didn't like being talked about behind our backs'.

528 'I would like a relationship'.

529 'Chigwell is limiting for friendships and relationships'.

530 'You are offered it, I have a social worker in the training centre and I have a psychologist but they know you they make their opinions and stick by them'.

Other comments made by participants during the course of the discussion

'I feel I am always moaning, always begging, making phone calls, writing letters. I get sick of it, so much paper work is involved, so may people to get past'.

'I find professionals patronising and not honest'.

'I have had to force everything, have had to fight for everything, the authority should notify you of your rights'.

'You should have a programme of care worked out so you know what you are getting and why'.

'We need a service where you can say "can you come in and help out"'.

'The hospital social worker was good, but we were told what to do. They don't seem to start from where you're at. I felt they were not trained in knowledge of disability'.

'I feel that older you are with a disability the less they bother with you'.

'At times when I needed to go for treatment they wouldn't take my wife in the ambulance. There's no other way for her to get there. It upset us both.

'The biggest help you can have is that they are aware of your illness and consequent needs and follow you through'.

'It has evolved over a few years that the support is there, people know us, people talk about things. Gradually as needs come along someone is always in a position to advise and see that it happens'.

'We need someone to do like you are doing, who asks if you can you manage and gives information instead of us having to ask'.

'I think professionals have a blinkered view'.

'You don't get any follow up'.

'You are the only one who has asked about what we want, what we feel. We feel professionals are looking after their own interests. It has added more stress because they have made us feel ungrateful'.

'It would be useful to have someone to go through how things are going. You don't always think to ask things, you don't know about things, you have to get on the 'phone to ask. Others get things why can't we?'

'I would like someone like you (to ask them how they manage) it should be Occupational Therapist's job, but we never see an Occupational Therapist'.

'Would like assessments from time to time so for example the bathroom could be more suitable, and I would not have bought that electric chair etc.'.

would like someone to liaise with to help sort out problems and tell them of their rights

'We like the idea of a spokes person to follow us up periodically. To ask us the sort of questions you are asking, it's made us think and prompted us, we get so tired in our routine and find it difficult to think of anything outside or any other possibilities'.

'I would like to participate in group discussions'.

'I would like to help in counselling if it would help others but I would need transport'.

'I would like to participate in a group discussion'.

'I would be keen on getting together with others to exchange information'.

'I would like to be part of a self advocacy group'.

'I would like to take part in a group'.

[illegible] to get [illegible]

[illegible] how they manage it [illegible] occupational therapist.

[illegible] for example the bathroom could be more sensible [illegible]

[illegible] of our problems and tell them of their [illegible]

[illegible] us periodically. To ask us how our [illegible] we get so tired in our [illegible] facilities.

[illegible]

[illegible] would be.

[illegible]

[illegible]

[illegible] group.

[illegible]