

Controlling Your Own Personal Assistance Services

The British Council of Organisations of Disabled People

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Part 1. Managing a Personal Assistant

Carl Ford and Richard Shaw

Introduction

At present, personal assistance services for disabled people are fragmented and vary considerably from area to area. As we all know this causes many problems for disabled people and their families. Self operated personal assistance schemes overcome many of these problems.

Self operated personal assistance schemes give disabled people and their families more independence, more control, and more freedom than any other form of provision currently available.

Running our own personal assistance services is not without its headaches. Employing and managing personal assistants (P.A's) may give us more control but it also carries with it certain responsibilities which need to be considered.

We believe the extra effort is a small price to pay for the benefits it brings. What follows then are some guide-lines on how to get started or setting up and managing your own personal assistance schemes. We hope you find them useful.

Assessing Your Personal Assistance Needs

Before employing a P.A it is important to know what your personal assistance needs are. Once you have worked this out you assess how much it is likely to cost. There are a number of ways this can be achieved. One way is to write down what you think your needs are on a personal assistance check list (see Example 1, page 8).

Funding

Once you have decided how much help you need you have to work out how long it will take in hours per day, days per week, and then how much it is likely to cost.

When you have done this you have to think about how to pay for it.

Most disabled people cannot afford to pay for P.A services themselves so they have to look for funding elsewhere. Money for personal assistance schemes may be available from a variety of sources such as the new Independent Living Fund, Local Authorities (Councils), charities, and in some cases compensation monies paid for personal injury.

Part 3 of this booklet tells you how to access money through the community care system.

Organisations like the Derbyshire Centre for Integrated Living (DCIL), Hampshire Centre for Independent Living (HCIL), the Spinal Injuries Association (SIA) or Greenwich Association of Disabled People (GAD) with expertise in this field can provide help and advice with funding packages and applications -their addresses are shown in appendix 1. Contact your local disability organisation or Social Services Department to find out if there is an Independent Living Support Scheme in your area.

Job Description

A job description is one way of ensuring that your P.A knows exactly what their duties are. When you are looking for staff it will help them to know exactly what you are looking for and whether they wish to apply. You can write a job description using your personal assistant check list (see Example 2, page 9).

You may decide to incorporate your job description into a letter which tells the prospective personal assistant something about yourself as well as your personal needs (see Example 3, page 12).

Advertising for Personal Assistants

Once you have decided what your personal assistance needs are you need to advertise for staff. There are a number of places where you can place your advertisement.

The local Job Centre will place advertisements on their display racks free of charge. Sometimes they provide special cards for you to fill in or you might have to provide your own. Local colleges offices also provide a good opportunity for free advertising for staff - particularly if you are looking for younger people to act as P.A's.

Details of how to place advertisements can usually be provided via the telephone, by post or in person.

Advertisements in local newspapers or journals can be effective but may be quite expensive. You can also place advertisements for P.A's in local supermarkets and shops. They are relatively cheap and provide a good way of recruiting local people if that is what you are looking for. A Recruiting Agency is another way of advertising -but they are usually quite expensive.

An advertisement for a P.A should be brief and include information on:

- the type of work
- hours per week
- pay
- how to get in touch with you

People should not display their address only their telephone or P.O Box number.

However, an advertisement could indicate the area you live in. Some individuals arrange with a friend or their local disability organization to receive the applications on their behalf. Some of these organisations have 'Pay and Display' boards.

How to Decide who to Employ

Once you have advertised and people have begun to reply you need to know more about them before you decide who to employ. You can do this by sending them an application form.

Application Forms

Application, forms are especially useful because they give you the opportunity to tell the applicant more about the Job and, at the same time, help you to 'weed out' unsuitable people.

You can use the information in your Job Description to help you write the form (see Example 4, page 15).

Interviewing

When you have received the application forms back you can decide who to interview. Interviews can be a daunting experience both for you and for job seekers. You might consider having a friend or relative present at the interview to provide moral support. They can also help with questions and can provide a second opinion if you are unsure about who to employ.

However, the key to good interviewing is to prepare well before the interview takes place. It is helpful to write down important questions and take notes of the applicant's answers on an interview Check list (see Example 5. page 17). This gives you an

opportunity to compare different applicant's responses once interviewing is over.

The important thing is to get as much information as possible at the interview in order to help you make your decision.

Contracts

Once you have decided to employ someone you may need to provide them with a Contract of 'Employment. Legally anyone who works for you for more than 16 hours per week or who has worked 8 or more hours per week for you for five years or more should have a contract of Employment or Statement of Terms and Conditions. Help with writing contracts can be provided by the organisations like those mentioned earlier, namely, Derbyshire Centre for Integrated Living (DCIL), Hampshire Centre for Independent Living (HCIL), the Spinal Injuries Association (SIA) or Greenwich Association of Disabled People (GAD). Your local Citizens

Advice Bureau (CAB) might also be able to help. Contact your local disability organisation or Social Services Department to find out if there is an Independent Living Support Scheme in our area.

Pay-roll Schemes

Accountability for direct finance is one of the most frequent reasons used to deny many disabled people full choice and control over their lives - particularly in relation to personal assistance. Not only do Pay-roll schemes provide essential methods for recording and managing personal assistance finance but they also effectively counter and nullify any argument of inadequate financial accountability. Pay roll schemes also ensure that your P.A's tax and National Insurance Contributions are deducted correctly. Hence they safeguard you and your P.A against any demands from the Inland Revenue or tax arrears or from the Contributions Agency for unpaid National Insurance contributions.

In terms of current scheme the 'Simplified Deduction Scheme'(SDS) and the 'Pay As You Earn (PAYE) Scheme' are the most common. The main difference between the two is simplicity and convenience depending on the method of operation. The SDS was initially introduced for domestic employees, particularly nannies, and is especially suited to P.A schemes as it is simple to operate.

Both the SDS and PAYE schemes can either be operated on a weekly, 4 weekly or a monthly system, depending upon payment arrangements. With the SDS there is marginally less responsibility on the employer for administration as this is simplified by the Inland Revenue particularly in relation to the individual employee's tax. Running a calendar monthly scheme rather than a weekly system greatly reduces the amount of administration involved.

Useful publications for all roll schemes use:

For the 'Simplified Deduction Scheme' ask for 'P40 Starter Pack' from your local Inland Revenue office. This should include a P12 Simplified Deduction Card, a P16 'How to Fill in the Simplified Deduction Card' and a P16a 'Taking on a New Employee' :

For the 'Pay As You Earn Scheme' (PAYE) you need a P4 'Starter Pack' from the Inland Revenue Office. Also ask for a copy of the 'Employer's Guide to PAYE'.

You can find the address of your local Inland Revenue office through British Telecom's Directory Enquiries. If the offices are inaccessible -as they often are - you can get the leaflets by asking for them to be sent to you by post.

Insurance

The first question that needs to be asked is "why do I need insurance when employing personal assistants"? The simple answer to this is that as an employer you have a legal duty to insure against accidents or injury to your staff, or accidents or injury caused by them while they are in your employ.

Accidents can happen in number of ways. For example, your P.A. might fall down the stairs while doing the housework..!'

Alternatively, they might have an accident outside your house while doing your shopping. If they are involved in a car crash they might also injure someone else. Additionally, your PA might contract an illness which they might feel is your responsibility - food poisoning, for example, contracted from eating your food. In such cases, as their employer, you might be held responsible. Consequently, when employing a P.A you must take out:

Employers Liability Insurance. This will insure you against your P.A having an accident or becoming ill while working for you, in cases where you might be held liable:

Public Liability Insurance'. This is needed to insure you against any damage or Injury caused to someone else by you or your, P.A while they are working for you.

You also need good comprehensive house insurance to cover your property and its contents. Sometimes P.A's can damage your property.

Sometimes 'Employers Liability Insurance' and 'Public Liability Insurance' can be included in a comprehensive household policy.

However, insurance can be quite expensive. Your funding agency -the Local Authority Independent Living Fund etc. - might help you cover the cost. You should also shop around to get the best terms.

It is also helpful to seek advice from organisations of people with experience of personal assistance such as the Derbyshire Centre for Integrated Living (DCIL), Hampshire Centre for Independent Living (HCIL), the Spinal Injuries Association (SIA) or the Greenwich Association of Disabled People (GAD) to ensure you are covered in all areas.

Rota Sheets and Work Sheets

Rota Sheets and work sheets provide users with an opportunity to plan personal assistants' duties and monitor wages (see Example 6, page 19). The examples provided are but one approach and simply a guide -many people devise their own system. The key is to maintain some form of record.

Part 2. The User/Personal Assistant Relationship

Carl Ford and Richard Shaw

It is important to remember that the user/personal assistant relationship is a very complex one. In most cases, it is a one to one relationship and on occasion can become very intense and personal. So we need to consider the vulnerability of both parties. In order to guard against any upsets which might occur we need to establish 'professional' boundaries. If both parties know exactly what their responsibilities are then there is less likely to be a problems.

It is important that both the disabled person and the P.A are able to communicate openly with each other. Problems and misunderstandings are more likely to occur if people do not talk to each other and know where they stand. If, for example, your P.A has smelly feet and it is causing you a problem how do you address it? Smoking can also be an issue; your P.A may smoke and you don't. To avoid these kinds of problems you need to

establish a set of 'house rules' so both parties know where they stand.

Alternatively, you may have certain habits or eccentricities which your P.A. might find offensive. In the even they need to be able to tell you in a way which does not jeopardise the working relationship.

Clear guide-lines will help to eliminate such problems. You can write them down yourself at the start of the relationship or you can identify them as you go along. Either way it is important that both parties know exactly what the guide-lines are and why they are there.

Privacy is another important consideration. On several levels your P.A is going to be privy -more or less - to everything you do. Often the more you limit the assistance you have the less choice you have in what you are able to do. Alternatively, the more assistance you have the less privacy you have. Some people prefer to have the minimum of assistance because they are not prepared to lose their privacy while others involve their P.A's in all their activities -financial affairs, social life etc. Here confidentiality is a key issue. If you choose the latter then you may make yourself more vulnerable. As a P.A user you have to decide what is a comfortable balance.

There is bound to be personality clashes in the user/P.A relationship. It can be particularly difficult when you have been employing someone for a long time and because of the nature of the relationship you have become quite friendly. When these clashes arise it is important that you have a set procedure with which to resolve them amicably without destroying that relationship.

Another problem for many P.A. users, particularly if they are new to employing their own staff, is learning how to delegate and

telling people what to do and what not to do. In many cases P.A' need to know what their responsibilities are without being told repeatedly. You don't want to have to tell your P.A to do the washing up every time you have ha a meal.

So for certain tasks you have to establish a set routine. Here a written check-list of P.A's tasks and responsibilities can be extremely helpful. If routine chores like 'watering the plants', 'walking the dog', 'washing the windows' are written down your P.A. will know exactly what they have to do and when.

For other daily tasks such as choice of meal or clothing the P.A user will want direct control. Consequently it is important for users to decide when to delegate and when not to.

It is also important that user remember that P.A.'s need to be respected as people and told when they are doing a good job. Such considerations can only strengthen and build a good working relationship. As disabled people, we know only too well how hurtful it is to have our humanity ignored or to be treated like an object. We should never allow ourselves to treat others as we may have been treated in the past.

Finally, it is important to re ember that at this point in time the job of P.A is not well recognised and doesn't have the status of other comparable occupations, We should take every opportunity to resolve this situation and try to give the work the status it deserves.

Example 1

Personal Assistant Check List

Personal Care

Getting up	How long does it take?
Going to bed	What is involved?
Night assistance	When and how long?
Washing	Special requirements?
Dressing	How much assistance is required?
Bladder and bowel care	Use of equipment? What time of day?
Grooming	Any special needs?
Exercise routine	Type and frequency?
Eating	How much assistance needed?

Domestic Needs

House cleaning	How often?
Shopping	Time involved?
Laundry/ironing	Time involved?
Meal preparation	What is included?
Maintenance of equipment and other household tasks	Planning and decision making?
Child care	Tasks involved?

Non-Domestic Needs

Employment	Routine?
Study	Number of days per week?
Visiting friends/relatives	How much assistance needed?
Meetings	How much assistance needed?
Entertainment	How much assistance needed?

Correspondence

How much assistance needed?

Paperwork/paying bills

How much assistance needed?

Example 2

A Job Description for a Personal Assistant

It is the job of the personal assistant to assist the disabled person in all areas of personal and domestic needs and to act as an escort and aid to the disabled person's social and day to day activities.

By providing assistance at the right time the disabled person is enabled to lead an individual and independent lifestyle in their own home within the community.

The personal assistant should understand their role in facilitating the self defined needs of the disabled person. They should feel confident to ask what the disabled person's needs, to always listen to the requests and to interpret them correctly.

Assistants should be able to handle the physical skills of lifting, handling, pushing and bending. The personal assistant does not have to be a strong person physically to do the job well. However, general good health is important.

Personal requirements

- Washing and bathing in bed or in bathroom.
- Grooming: attention to hair, nails, feet, skin, eyes etc.
- Dealing with continence management. Assisting in maintaining, a bowel and bladder routine.
- Assistance dressing and undressing.
- Helping in and out of bed/wheelchair. Assistance to turn in bed and toileting during the night when providing sleeping in cover.
- Daily Physiotherapy exercises. Movement of limbs as required, mainly in the mornings.

- Serving and cutting of food as required.
- General domestic duties.
- Making and changing of beds.
- Assisting with shopping and other associated tasks
- Preparing and corking of meals
- Assistance with looking after children
- General housework, including the cleaning and dusting of rooms, furniture and fitments and other household maintenance.

Other duties

- Preparation of car in mornings and prior to use and general cleaning of the vehicle.
- Assistance in and out of car
- Maintenance to exterior of house; i.e. clearance of snow from paths, cleaning windows etc.
- Upkeep and maintenance of equipment; i.e., wheelchairs, hoists and other technical aids.
- Escorting to business and social meetings and events

Note: All needs will vary daily and the personal assistant's duties and tasks will fluctuate accordingly.

Personal Assistants Responsibilities

As far as possible resolve any questions regarding the job prior to beginning work.

Arrive at the agreed time ready to work. Give notification if you are going to be more than ten minutes late.

It is important to establish a close working relationship when working on a one to one basis. If any problems arise it is important to discuss and resolve them as soon as possible. Be as open in your communication as possible.

Confidentiality: respect the privacy of the person you are working with. Many problems can arise from casual conversation about the help and assistance you might give. Try to maintain a professional approach at all times.

Attitude: appreciate the strains and stresses involved for the disabled person and the effect that this can have on the acceptance of help. Understand that the preservation of dignity and independence is important.

Learning the Tasks involved

For the most part, areas of assistance can be learned and familiarised through the assistant and disabled person working together. Where required practical training and guidance will be provided.

Points to Bear in Mind

Personal assistants should respect the possessions of and equipment in the disabled person's home. Use of the telephone, television, radio, etc. should only be with the disabled person's prior consent.

Qualifications and Personal Qualities Required

Personal assistants should be:

- reliable and trustworthy;
- be able to accept responsibility;
- be able to work on their own and work with initiative as the occasion arises;
- clean and have no unhygienic habits;
- willing to learn the job well;
- diligent;
- conscientious.

Example 3

Information for prospective Personal Assistant

Following a driving accident in June 1986 when I was aged 24 I am now a wheelchair user. I broke my neck and have little movement or sensation below my shoulders. I can, however, move my arms, although not perfectly and I am able to do many things around the house -eating, drinking, shaving etc. -and at work use a computer and a telephone. I can also drive.

There are, though, other things with which I need help, such as getting in and out of bed, dressing, transferring to and from a car - it is for these things and general help around the house that I employ personal assistants.

I find this rewarding in many ways: I am able to live in an active and interesting way,-in the way I choose, and gain an insight into life elsewhere. The Personal assistant's work is very much appreciated and all those who have worked for me have made many friends and enjoyed their time here.

Specific Tasks

Each day I need help dressing and getting out of bed - I generally leave for work at around 8.30 am.

I require the apartment to be kept clean and the usual washing and ironing to be done. Normal shopping and cooking is also needed. I am not a vegetarian and I am not on a special diet. There will certainly be generous amounts of spare time during the day. Some staff in the past have used this time to attend an excellent language school at Lancaster University - others have taken part time jobs or gone horse riding nearby.

Two nights a week I attend night school and need to be driven there and back. I have both a manual and an automatic car. Each evening I also need help undressing and getting into bed.

The method of moving from wheelchair to bed/car is by a special lift known as a Standing Transfer. This lift has been devised by physiotherapists to make lifting easy and removes any danger of straining the lifters back. Full training will be given in the use of the Standing Transfer. I am 5 feet 10 inches tall and weigh 10 stone. Anyone of 5 foot 2 inches and 8 stone or more can lift me easily.

I will also need help with toileting and showering. Again full training will be given on the use of suppositories and any other special equipment.

No experience or knowledge of nursing is needed -just a willingness to learn. Normally, it takes less than 2 weeks to learn the routine and help is always near at hand.

Living Arrangements

My apartment is attached to my parent's home and they are invariably close by should assistance be needed. In fact I work

with my father. I work in advertising and marketing and there may be occasions when help in the office is needed.

Your room is in their house; it is private and allows you your own space. It has a hi-fi and a colour TV. A private bathroom is provided. The house is in a beautiful part of Lancashire and has a large garden, dogs, a cat and some chickens. There is easy access to the Lake District National Park, the Yorkshire Dales and the cities of Lancaster, Manchester and Liverpool.

You will have access to a small manual Suzuki van which has been adapted to take a wheelchair as well as an automatic Vauxhall Astra which I am able to drive too.

Time off is by arrangement. As described above there is a good deal of free time during the day but I normally try and give one evening a week free together with weekends if I visit friends living locally.

It is certainly possible to arrange for your friends to stay and visit.

About the Area

My home is in a small village approximately 3 miles from 2 small towns and 12 miles from the city of Lancaster. Our village has good train and bus links to local towns and on to the national transport networks. Living in a village you will find that there is much to do if efforts are made to find activities that interest you - the area is busy but is not one of bright lights and ready made entertainment like London. Lancaster is the twin town of Aalberg in Denmark and has good shops and excellent educational and sports facilities at the University.

The area is one of great natural beauty with walks in the hills and around the lakes in nearby National Parks. The larger cities of Manchester, Preston and Liverpool are within 1 hours drive and have excellent shopping and other facilities.

I enjoy going out to eat, the cinema, theatre and seeing friends. Other interests include driving, sports, reading and music.

Qualifications and Employment Arrangements

No formal qualifications are needed except a driving licence. Desirable qualities are a sense of humour, general fitness and well being, a degree of patience, a willingness to learn and a willingness to live as a member of a happy, busy and active household. I do not smoke and smoking will not be permitted in my apartment although it is in my parent's house and in your room.

Normally I work on a one week trial period to see if you will be happy with the work and living here. If so I usually agree a time scale of 3/6/9 months with any problems or queries tackled as they appear -holidays are by arrangement.

The pay is in addition to all reasonable living costs except telephone and I always pay one week in arrears on a Friday with any taxes to be discussed.

Example 4

An Application Form

Within the nature of the work for which you are applying this position is exempt from the provisions of Section 4(2) of the Rehabilitation of Offenders Act 1974, by virtue of the Rehabilitation of Offenders Act 1974 (Exemptions) Order 1975. Applicants are therefore not entitled to withhold information about convictions which for other purposes are 'spent' under the provisions of this Act. In the event of employment, any failure to disclose such convictions could result in dismissal. Information given is confidential and will only be considered for the purposes of this application.

1. Full name
2. Address
3. Telephone Number
4. Age
5. Nationality
6. Religion
7. Do you smoke?
8. Do you hold a current driving licence?
9. Details of any convictions or endorsements
10. Do you have your own transport?
11. How would you travel to work?
12. Are you willing to work regular weekends?
13. Are you willing to 'sleep in' occasionally?
14. Are you able to respond to "crisis" call outs?
15. Details of any experience of residential or care work?
16. Do you mind animals?
17. Any hobbies or special interests?
18. Educational Qualifications.
19. Why are you applying for this job?

20. Please give details of previous employment history:

Name and Address of Employer Description	Start/Finish	Job
---	--------------	-----

21. Name and Address of two Referees (one personal, one professional)

1

2

22. When would you be able to start?

23. Any additional information relevant to this Application.

24. The particulars entered by me are to the best of my knowledge a true and complete record.

Signature

Date

Example 5

Interview Check List

Name

Address

Telephone

Where did you see the post advertised?

Date

Age

Do you have a current driving Licence?

Do you have your own transport?

Are you a smoker or a non smoker?

Can you cook?

Are you able to work flexible hours?

Are you able to work split shifts?

Will you require accommodation?

Do you have any health problems?

Have you any personal commitments?

(As appropriate) How does your partner view this type of work?

Have you any previous experience of this type of work?

What are your personal interests?

Do you mind working a trial period?

Have you any references from your previous employer?
Why did you apply for this particular, post?

COMMENTS:-

Example 6

Personal Assistance Rota and Work Sheet

PERSONAL ASSISTANT ROTA

Week commencing 199..

Team Day	Name/ Time	Name/ Time	Name/ Time	Name/ Time	Name/ Time
Mon					
Tue					
Wed					
Thur					
Fri					
Sat					
Sun					

WORK SHEET

Date	Time	Rate	Earnings
------	------	------	----------

		£	
		£	
		£	
		£	
		£	
		£	
		£	
Total			

PART 3. How To Get The Money To Pay For Personal Assistance And Have Control Over How It Is Spent.

JENNY MORRIS

The two main sources of funding for personal assistance are social services departments and the Independent Living (1993) Fund. A third possibility, if you are in paid employment, (including self employment) is the Access to Work scheme. This section of the booklet deals with the first two sources, with brief information being given about the Access to Work scheme at the end.

You can get control over the money that you need to employ personal assistants through using a combination of the community care system, the rights that disabled people have under the 1986 Disabled Persons Act and the 1970 Chronically Sick and Disabled Persons Act, and the initiatives developed by disabled People and their organisations.

Getting into the system

Ask your social services department for an assessment of your needs for personal assistance.

Your local Social Services Department will be listed in the telephone directory under your local Council.

Section 4 of the Disabled Persons Act (1986) says that, if you come under the legal definition of a 'disabled person' (laid down by the National Assistance Act 1948) you have the right to an assessment of your needs for all the things which are covered under Section 2 of the Chronically Sick and Disabled Persons Act 1970.

Section 2 of the 1970 Act covers:

- practical help in your home
- radio, television
- to use a library or similar facilities
- to go to lectures, games, outing or other recreational activities outside your home, or assistance in taking advantage of educational facilities
- help with transport to any of these activities
- adaptation to your home, or equipment for your 'greater safety, comfort or convenience'
- holidays
- meals in your home or elsewhere
- a telephone and any special equipment necessary to enable you to use it

As you can see, what the 1970 Act covers is limited but (a) you have the right to be assessed for these things and (b) if you are assessed as needing them then your social services department must arrange for them to be provided. (See Your Rights to Housing and Support, details at the end of this section, for more information.)

Under the new community care system, social services; departments have been advised by government to assess people's need for six main categories of things:

- personal/social care
- health care

- accommodation
- finance
- education/employment/leisure
- transport/access

(Department of Health Social Services Inspectorate (1991), Care Management and Assessment: Summary of Practice Guidance, HMSO, PP. 10-11)

So, when you ask for assessment of your needs, it should cover all these things - that is, it should take into account your whole life and what is required to live independently -but you will only have a right to the things which are covered under Section 2 of the 1970 Act.

Make sure that you get a 'needs-led' and not a 'service-led' assessment

The community care reforms involve new ways of doing assessments (including assessments for the things covered under Section 2 of the 1970 Act). According to government guidance, these are now supposed to be needs-led rather than service-led. The advantage of this is that needs-led assessments are based on a social model of disability. In other words, needs-led assessments are not a measure of what you can't do nor are they an assessment of whether you fit the criteria for existing services.

Instead needs-led assessments establish what it is you want do in your life, what you have difficulty doing and what kind of help you need to enable you to do these things. So for example, a needs led assessment will say: this person needs practical help with getting dressed in the morning. It will not say: this person needs a home care service; it will not involve ticking boxes to establish 'dependency' levels (i.e. what you can't physically do).

There are varying levels of understanding amongst social services workers about needs-led assessments. It will help if you

are clear what a needs-led assessment is so that you put your needs forward in terms of what you want to do in your daily life and the help you need to do it.

Being your own care manager'

Once your needs have been assessed a care manager (who may be the same person who did the assessment) will decide, in consultation with you, how those needs are going to be met. Social services departments have now been divided into purchasers of services and providers of services. Care managers are purchasers; people who run home care services and day centres are providers. Care managers will either hold a budget, or will work with a senior care manager who holds a budget, and will decide how the money that has been allocated to meet your needs should be spent.

The situation that you want to establish is whether you are your own care manager. In other words, where you have control over how the money which has been allocated to you is spent. It is this control which will enable you to recruit your own personal assistants. The government supports the idea of disabled people being their own care manager. Their guidance to social services departments says: 'It may be possible for some service users to play a more active part in their own care management, for example assuming responsibility for the day to day management of their carers may help to meet the aspirations of severely physically disabled people to be as independent as possible.' (Department of Health, Community Care in the Next Decade and Beyond: Policy Guidance, HMSQ, 1990, p.25)

There are a number of ways in which you can be given control over how social services money is spent which will enable you to recruit and manage your own helpers. However, before we look at these, we, need to look at the Independent Living (1993) Fund.

THE INDEPENDENT LIVING (1993) FUND

If you are eligible for a cash grant from the Independent Living (1993) Fund, the social services department will want you to apply for one as this will reduce the amount of money they have to contribute towards your personal assistance costs.

To be eligible for an Independent Living (1993) Fund grant you must:

- be at least 16 years of age and under 66 years of age
- be receiving the highest care part of the Disability Living Allowance
- be able to live in your own home for at least the next six months
- live alone or with people who cannot provide all the help you need
- have savings of less than £8,000 (however, if you have savings set aside for a piece of equipment, adaptation or vehicle which you need because of your impairment these savings may be ignored)
- receive income support, or receive income at the same level or less than income support, or if you have income which is more than you would get on income support be less than the amount you need to pay for help
- your social services department must have agreed to give you services which cost them £200 per week to provide for you

One important advantage of an ILF grant is that the money is paid direct to you and you can therefore use it to employ personal assistants. However, there are two other important points to bear in mind:

- cash grants from the ILF are means-tested. Although it is possible to be in paid work and still receive money from the ILF, they will assume that some of your income is available for paying for your personal assistance. The ILF have a particular

way of calculating how much you would have to pay and further details of this can be obtained from them (see address at the end of this section). In contrast, most direct/indirect payment schemes (see below) developed by social services departments are not means-tested -although they may be in the future.

- if your personal assistance needs are more than £500 per week in total (i.e. the £200 from the local authority plus the £300 from the ILF), then you cannot get a cash grant from the ILF. In other words, your social services department will have to pay the whole cost of the help you need. There is pressure on the government to change these amounts so you will need to check whether these figures are up to date.

Most social services departments will have a policy of the maximum amount which they will spend on each person (they usually decide this according to which 'client group' you come under). Ask them how much this is. Ask them also what arrangements they have for people who have particularly high personal assistance needs, as they will usually have a procedure for allocating more than the maximum in particular cases.

How Social Services Money Can Be Used To Give You Control Over Personal Assistance

Over the past few years, disabled people and disability organisations have - together with some social services departments -developed ways of using social services budgets which enable people to employ their own personal assistants.

The main obstacle to doing this has been the government's opposition to 'direct payments' but many ways around this have been found.

Direct Payments

The term 'direct payments' is used to refer to a cash grant which a statutory agency makes to an individual to enable them to purchase the help they need.

The government has said (in the past) that social services authorities are not allowed to make direct payments (because sections of the National Assistance Act 1948, the Health Services and Public Health Act 1968 and the National Health Service Act 1977 say that social services authorities should not make cash payments to individuals instead of providing services). However, the Government has now announced its intention of introducing new legislation to make it possible for direct payments to be made.

Already, a small number of social services authorities make direct payments to people-to enable them to employ their own helpers. Shropshire County--Council is one social services authority who are making direct payments but they have now restricted this to those to whom they already make payments. However, if you want to find out more about direct payments, Val Suffolk from Shropshire Social Services is willing to give more information (Tel. 01743 255843).

Indirect Payments: (a) 'Third Party' systems

This refers to the situation where a social services department pays a cash grant to a voluntary organisation on behalf of an individual's personal assistance needs and the voluntary organisation then passes it on to the person who employs their own helpers. This is becoming increasingly common.

One example is that of Lothian Social Work Department who, having assessed someone's personal assistance needs, make a quarterly cash payment in advance for the cost of paying for that assistance to the Edinburgh Voluntary Organisation Council. They pass the payment on to the individual who then uses it to either employ their own personal assistants, or to employ agency staff.

Further information from Suselle Bottey, Development Worker for Independent Living Schemes, Tel: 0131 5569140.

Wiltshire Social Services Department are also operating this kind of third party system, through the Wiltshire Community Foundation. Payments are made to individuals into a separate bank account which is used to pay personal assistants or to pay agencies. Wiltshire are also funding the local disability organisation (Wiltshire User Involvement Network) to provide support to individuals who receive cash payments so that people can get help with recruitment, dealing with tax and national insurance, etc.

Further information from Dilys Fisher, Wiltshire Independent Living Fund Support Co-ordinator, Tel: 01380720577. This organisation also has a worker who helps Black and Asian people to set up independent living schemes (Mayur Bhatt, Development Worker for the Living Options Partnership Project).

Indirect Payments: (b) Trusts

A local authority can set up a non-charitable Trust for the benefit of an individual. This means that the local authority hands an agreed sum of money over each year to a Trust which is set up for the benefit of individual or individuals. In the case of one individual, there are usually 3 or 4 Trustees, of whom the individual (the 'Principal Beneficiary') is one and the day-to-day management of the Trust is delegated to this person. The other Trustees can be friends, a solicitor, an accountant or anyone else who you think would be useful to you.

For taxation purposes, the money received from the local authority is treated as capital and therefore does not incur income tax. Capital gains tax will not be incurred because all the money will be spent on personal assistance. However, if interest is

received on the money while it is held in building society or bank account this will incur income tax (normally deducted at source).

An increasing number of social services departments are interested in setting up Trusts as one way of financing personal assistance. Bill Walsh, who got his local authority to set up a Trust for him, has produced an information booklet about how to do it. It is also possible to purchase a copy of his Trust Deed (unfortunately the London Borough of Tower Hamlets insist on charging £100 for it).

Further information from Bill Walsh, 13 John's Place, London, E1.
Tel: 0171 790
8973.

June Maelzer, whose local authority set up the first Trust that we know of (in 1986) is willing to give advice to individual users and provide consultancy to social services departments on how to set up a Trust.

Further information from June Maelzer, 101 Burnage Lane,
Burnage, Manchester, M19 2WN. Tel: 0161 224 3534.

Time-sheet systems

An example of this kind of system is the London Borough of Camden's Independent Living Scheme. People can refer themselves to the Supported Living Team who will then discuss with them what their personal assistance needs are, taking account of the person's life as a whole -i.e. personal assistance needs related to employment and social activities as well as personal care. The majority of users of the scheme require 24 hour personal assistance but some need just a few hours per week. The scheme is flexible and tailored to the individual's need.

Once an agreement has been reached about how much help someone needs, then the person can recruit their own personal

assistants. As the scheme has been going for 10 years there is a network of experienced P.A.s. If the user wants help with recruitment this can be provided by the scheme's Co-ordinator.

The personal assistants are treated as self-employed. This has been a matter of long-running discussion with the Department of Social Security and the Inland Revenue. Recently the DSS have accepted that the P.A.s are self-employed but the matter remains unresolved with the Inland Revenue. Each week, a time-sheet is completed by the user and P .A. and submitted to the Council who process it and pay the P .A. within five days.

Further information from Christine Satwick, Co-ordinator, Supported Living Team, London Borough of Camden Social Services Department -Tel No: 0171 2784444 Ext: 6683.

The Merton Association for Independent Access (MAFIA -an organisation controlled by disabled people) operates a time-sheet system on behalf-of their social services department. A social worker assesses someone's needs and agrees that they can employ personal assistants to provide so many hours help. MAFIA helps with the recruitment and any other support required. Time-sheets are presented to them every week which are then paid by MAFIA from money given to them by the Social Services Department. In this case, the personal assistants are employed by MAFIA and they deal with all the tax and national insurance, etc.

Further information from Merton Association for Independent Access, Vestry Hall, London Road, Mitcham, Surrey, CR4 3UD. Tel: 0181 6406587.

The Independent Living Fund replacement money:

This is another development which opens up more opportunities for the funding of personal assistance. Each social services department has received a special grant from the government to

'replace' the money which it is calculated disabled people living in their area would have received under the old Independent Living Fund. For many areas, by 1995/6 this will be £4/500,000. Many social services departments are setting this money aside especially for people with physical and sensory impairments who have high personal assistance needs-. Ask your social services department what they are doing with the money.

Independent Living Support Schemes

It is possible for a social services department to set up, or to fund a disability organisation to set up, an Independent living support scheme, possibly using the Independent living Fund replacement money.

Developing such Independent Living support schemes is very important. Although as individuals we want purchasing power - and this is why direct payments are the best way of giving people choice and control -we don't want to be isolated individuals all struggling to survive on our own, dealing on our own with the difficulties of managing independent living. We need to learn from each other, and have the security of knowing that the support we need is there. Social services departments can resource these support needs, using the expertise within the disability movement and the support and training services which the disability movement has itself created. It's just as important that we encourage social services departments to develop this kind of service as it is that we encourage them to develop direct and indirect payment systems.

THE ACCESS TO WORK SCHEME

If you are in paid employment (including self-employment) you can get personal assistance costs associated with work funded through' the Access to Work scheme. This scheme was introduced in June 199A- and

is run by the Department of Employment. Access to Work can pay for:

- a communicator for people who are deaf or have a hearing impairment
- a part-time reader or assistance at work for someone who has a visual impairment
- a support worker if someone needs practical help either at work or getting to work.

The scheme can also pay for equipment, adaptations to a car, taxi fares or other transport costs, and alterations to the work environment. The Placing, Assessment and Counselling Teams (PACTs) run the scheme and you can find your local PACT in the telephone directory under 'Employment Service' (or ring your local Job centre) .

References:

Your Rights to Housing and Support, available from SIA, 76 St James's Lane, London, N10 3DF (£6.00 inc. p+p). Tel: 0181 4442121

Independent Living (1993) Fund, P.O. BOX 183, Nottingham NG8 3RD Tel: 01159 428191/428192.

How to set up Trusts and User Controlled Independent Living Schemes, available from Disability Advocacy Network, Disability Resource Centre, 40-50 Southern Grove, London, E3 4PX. Tel: 0181 980 2200. (£3 + P&P for disabled people).

Appendix 1

Useful Organisations

Avon Centre for Independent Living has recently changed its name to The West of England CIL, Courtlands, Leinster Ave, Knowle, Bristol, BS4 1 AR. Telephone: 01179839839.

British Council of Organisations of Disabled People, Litchurch Plaza, Litchurch Lane, Derby, DE24 BAA. Telephone: 01332 295551.

Derbyshire Centre for Integrated Living, (DCIL) Long Close, Cemetery Lane, Ripley, Derbyshire, DE5 3HY. Telephone: 01773 740246.

Disability Alliance, Universal House, 88 -94 Wentworth Street, London, E1 7SA. Telephone: 0171 247 8776.

Disability Direct. Rosehill Business Centre, Normanton Road, Derby, DE23 6RH. Telephone 01332 299449.

Disablement Income Group, (DIG) Unit 5, Archway Business Centre, 19-23 Wedmore Street, London, N19 4RZ. Telephone: 0171 263 3981.

Disabled Living Foundation, Telephone: 0171 289 6111.
380 -384 Harrow Road, London, W9 2HU.

Disability Resource Team, (DRT) 3rd Floor, Bedford House, 125 - 133 Camden High Street, London, NW1 7JR. Telephone: 0171 482 4896.

Greater London Association of Disabled People, (GLAD) 336 Brixton Road, London, SW9 7AA. Telephone: 0171 2740107.

Greater Manchester Coalition of Disabled People, (GMCDP). Carisbrook, Wenlock Way, Gorton, Manchester, M12 5HF. Telephone: 0161 2735154/5.

Greenwich Association of Disabled People, (GAD), Greenwich Centre for Independent Living, Christchurch Forum, Trafalgar Road, Greenwich, London, SE1 0 9EO. Telephone: 0181 305 221.

Hampshire Centre for Independent Living, (HCIL) 4 Plantation Way, Whitehall, Bordon, Hampshire, GU35 9HD. Telephone: 01420474261.

Independent Living Alternatives, Fulton House, Fulton Road, Wembley Park, Middlesex, HA9 0TF. Telephone: 0181 9028998 ext: 228.

Islington Disablement Association, (IDA) 90 -92 Upper Street, London, N1 ONP. Telephone: 0171 226 0137.

Lambeth Centre for Integrated Living, (LCIL) Barstow Crescent, Palace Road, London, SW2 3NS. Telephone: 0181 671 8892.

Lothian Centre For Integrated Living, (LCIL) EH6 8BR. Telephone: 0131 553 6999.

Lochend Road, Edinburgh, Lothian,

Muscle Power. Rosehill Business Centre, Normanton Road, Derby, D,E23 6RH Telephone 01332 299449.

REGARD, BM REGARD, London, WC1 N 31X.

Shropshire Disability Consortium, The Shropshire Disability Resource Centre, Lancaster Road, Harlescott, Shrewsbury, Shropshire, SY1 3NJ. Telephone: 01743 344599 Ext: 236.

Southampton Centre For Independent Living, (SCIL) Southampton, 6 Northlands Road, S01 2LF. Telephone: 01703 330982.

Spinal Injuries Association, (SIA) 76 St James' Lane, Muswell Hill, London, N 10 3DF. Telephone: 0181 444 2121.

Appendix 2

Resources

Essential Publications for Personal Assistance Users

'Guide-lines for Self Operated Care Scheme Users. Greenwich Centre for Independent Living, Christchurch Forum, Trafalgar Road, Greenwich, London, SE10 9EQ. Telephone: 0181 305 2221.

Sourcebook Towards Independent Living'. HCIL Books, c/o Mark Walsh, 31 Churchfield Headley, Bordon, Hampshire GU35 8TF.

'The Personal Assistance Users Newsletter'. BCODP, Litchurch Plaza, Litchurch Lane, Derby, DE24 BAA. Telephone: 01332 295551

The Department of Employment publish booklets on 'Employment Legislation'. These can be obtained free from your Employment Services offices. These range from PL699 to PL870. Of particular use is PL 700 entitled 'Written Statement of Main Terms and Conditions of Employment'.

The ACAS advisory handbook 'Discipline at Work' can be obtained from ACAS Reader I PO Box 797, London. SE84JX. Telephone Enquiries: 0171 396 5100.

'Your Rights to Housing and Support'. Spinal Injuries Association. 76 St James' Lane, London, N10 3DF. Tel: 01814442121.

'User Control and Employing Personal Assistants for independent Living'. Disability Advocacy Network. 40-50 Southern Grove, London, E3 4PX. Tel: 0181 9802200.

Statutory Authorities

Health Authorities should provide information on health related services like chiropody, physiotherapy, health visitors, district nurses and so on. Your GP should be able to provide information on these services. Local Community Health Councils can also be a good source of information.

Department of Social Security/Benefits Agency -they are sometimes useful for information on benefits and social security entitlements.

Department of Health -they can provide information on impairment related technical aids such as wheelchairs, splints and callipers.

Council Housing Departments -contact for housing problems and information about grants such as the Disabled Facilities Grant for adapting inaccessible homes. They provide these grants to help with adaptations. However, Social Services Departments also have a legal duty to ensure that disabled people get the adaptations they need. So contact both Housing and Social Services regarding adaptations.

Local Authority -contact Local Authority Social Services Departments for Home Helps, Occupational Therapists, Technical Aids, 'Respite Care' service etc.

The address and telephone number of each of the above will be in your local telephone directory and can also be obtained from British Telecom's Directory Enquiries.

Funding

Housing, Disabled Facilities Grant - contact local authority housing department (see above).

Part 3 of this booklet explained how to get funding for personal assistance, including-how to make contact with other disabled people who have got funding for personal assistance. Your local Social Services Dept is probably the best place to start to get this information and they are listed in your telephone directory under your local Council.

Personal Assistance

Active Assistance, 2nd Floor Office, Stricklandgate, Kendal, Cumbria, LA9 4RA. Telephone: 01539 730674.

Community Service Volunteers, (CSV Independent Living Scheme) 237 Pentonville Road, London, N1 9NJ. Telephone: 0171 2786601.

Spinal Injuries Association, (SIA) (see above).

United Kingdom Homecare Association, (UKHCA) The UKHCA Secretariat, Premier House, Rayburn Terrace, Watson Mill Lane, Sowerby Bridge, West Yorkshire, HX6 3BW.