

MAKING OUR OWN CHOICES

Independent Living, Personal Assistance
And Disabled People

Report of the BCODP Seminar on
Independent Living and Personal
Assistance

Herewood College, Coventry

August 7, 8, 9, 1992

EDITED BY
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**THE BRITISH COUNCIL OF
ORGANISATIONS OF DISABLED PEOPLE**

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Prologue

The BCODP Independent Living Committee was formed in 1989 as a direct result of disabled people who were personal assistant users coming together throughout the whole of Europe. With the European community drawing together socially, economically and politically, disabled people also felt the need to work together. Disabled people interested in independent living issues from 14 different European countries assembled at the European Parliament in Strasbourg for four days and discussed, debated and conceived the Strasbourg Independent Living Resolutions and formed the European Network on Independent Living (ENIL). The disabled representatives from the UK returned home and through BCODP founded the Independent Living Committee to promote and develop personal assistance and independent living issues in the UK.

Starting from such a position of strength we had the right ingredients for success. One of the committees earliest objectives and visions was to organise seminars around independent living issues with the purpose of targeting and involving new disabled people in an independent living lifestyle. The two seminars which came out of this group were the beginning of part of this vision becoming reality. The Rowntree Foundation demonstrated great wisdom in seeing the value of such seminars and consequently provided the grant to enable them to happen. We hope that these seminars are the beginning of a series of seminars or forums exploring and developing the many aspects of this unique way of living. Many of the participants expressed a great thirst for more knowledge in the various modes and aspects of independent living.

For me the seminars were a wholly unique experience. These were not just seminars in the usual format with talks, presentations, workshops, feedbacks and personal reflections, but seminars which had the extra dynamic of being seminars of direct learning and action. Participants, most of whom were new to the ideas and ways of independent living, not only had to concentrate and absorb the contents of the presentations, participate and question aspects of these talks in the workshops, but also had to put into practise throughout the entire weekend the skills involved in communicating, organising and directing the use of personal assistants which were provided for people who didn't have their own. Consequently as a result of personal assistants being provided over the weekend there was a multi-dimensional nature to the whole seminar both in the sessions and in the free time available.

What was extraordinary about the seminars was witnessing people growing throughout the course of the weekend as they became more at ease and confident as time went on. Another dynamic feature was that people were not alone in going through this learning process because there was a great sense of sharing amongst the participants in terms of information, advice and experience. This was possible because of the mix between new and older independent living practitioners and advocates. In fact there was a very positive spirit of co-operation and endeavour throughout, by both the participants and the personal assistants.

It is with great credit to the seminar organisers Colin Barnes and Paul Lindoe and their hard-working support/advisory groups, that such a wide range of people including those in residential care or living with their families, older people, disabled people from black and ethnic minority communities, disabled lesbian and gays and young disabled teenagers were able to come together. It was our major priority to make sure that all marginalised groups had access to the conference and felt comfortable in making equal contributions. This would not have been achieved without the support groups work and I would personally like to thank them here. Finally, I would also like to thank all the participants for making both seminars such successful and significant events and to the personal assistants for their invaluable role in it all.

This was the first time that residential seminars of this particular nature had been organised in this country. They were exploratory in sounding out the knowledge and feelings of disabled people about this way of life. The concluding result was that the idea, philosophy and way of life of independent living is alive, strong, dynamic, and bursting for future developments. This must be one of the most fundamental ways in empowering disabled people in becoming active and equal citizens in this country.

Jane Campbell
Co-Chair BCODP June 1993

Preface and Acknowledgements

The British Council of Organisations of Disabled People (BCODP) is Britain's national umbrella for organisations controlled and run by disabled people. A founder member of Disabled People's International (DPI) the BCODP has, since its formation in 1981, been at the forefront of the international struggle for equal rights and opportunities for disabled people. Today, the BCODP has some 95 member organisations and represents over 300,000 disabled people and their supporters.

For disabled people 'independent living' and 'personal assistance' are fundamental to equality of opportunity. They are basic human rights which have yet to be accorded the overwhelming majority of disabled people in the United Kingdom. In view of this situation the BCODP Independent Living Committee decided to hold two free national seminars on independent living and personal assistance for disabled people. This Report documents the events leading up to and during the first of these two ground breaking seminars?

From the outset the organisation of the Seminar was under the direction of the BCODP Independent Living Committee and a Seminar Support Group including: Lata Allman (Leicestershire Coalition of Disabled People); Maggie Davis (Derbyshire Coalition of Disabled People); Carl Ford (Shropshire Disability Consortium and BCODP Independent Living Committee); and Richard Shaw (Derbyshire Centre for Integrated Living and BCODP Independent Living Committee). This event could not have taken place without their enthusiasm, help and co-operation. Funding was provided by the Joseph Rowntree Foundation and administrative facilities supplied by the BCODP Research Unit in the Department of Social Policy and Sociology at the University of Leeds.

Special thanks must also go to the speakers at the Seminar: Stewart Bracking (Muscle Power), Carl Ford, Richard Shaw, Deborah Kent (Independent Living Fund), Anne Rae (North West Shape), Nasa Begum, Dennis Killin (REGARD), John Evans (Hampshire Coalition of Disabled People and Deputy Chair of the BCODP), for providing their services free of charge. I would like to thank the following organisations for providing an abundance of relevant and free information for Seminar participants: Derbyshire Coalition of Disabled People (DCDP), Derbyshire Centre for Integrated Living (DCIL), Greater Manchester Coalition of Disabled People (GMCDP), Hampshire Centre for Independent Living (HCIL), the Independent Living Fund (ILF), Lothian Centre for

Integrated Living (LCIL), Muscle Power, REGARD, and the Spinal Injuries Association (SIA); the Tragic But Brave Roadshow for one of the most entertaining and thought provoking cabarets in the country; and, last but by no means least, all those - both disabled people and personal assistants - who by attending and contributing to both the formal and informal discussions during the Seminar help make it a truly remarkable event.

Colin Barnes
Seminar Co-ordinator,
June 1993

1. Introduction

Background

In the summer of 1991 the British Council of Organisations of Disabled People's (BCODP) Independent Living Committee elected to organise two national seminars on 'independent living and personal assistance' for disabled people. The twin aims of these events were to develop further the principles of 'independent living' for disabled people and to introduce newcomers to the disability rights movement to self operated personal assistance schemes.

The need for such a project emerged mainly because of successive British Government's failure to introduce policies which will enable disabled people to achieve meaningful independent/integrated living within the community -this is particularly relevant to self operated personal assistance schemes. Hence, the bulk of Britain's housing, schools and colleges, employment opportunities, transport and amenities remain inaccessible to disabled people, and essential personal and domestic services go underfunded and controlled by local authorities, health authorities, private agencies or, increasingly, charities.

As a consequence, the majority of disabled people in Britain are forced to endure a lifestyle characterised by unrelenting poverty, social isolation, enforced and unnecessary dependence upon informal support systems provided by family, friends and loved ones. For many it is a lifestyle accompanied by the insidious fear of eventual incarceration in a residential institution in the event that their informal support system breaks down. Indeed, Government figures show that as many as 422,000 people, 20 per cent of whom are below retirement age, have little choice but to live in institutions.

This is despite the fact that the international disability rights movement has repeatedly demonstrated that no-one regardless of impairment or age need waste their lives in an institution if provided with appropriate services and support within the community. Moreover, it has campaigned vigorously for the implementation of such facilities as of right (see Appendix 1 and 2). These two seminars are an important part of that campaign. This Report outlines the sequence of events leading up to and during the first of these seminars.

Organisation

It was decided that the first Seminar was to be for people living in the North of England, Scotland and Wales and it was to be a two day event. The organisers hoped to bring together fifty established personal assistance users and people with 'severe' physical impairments currently using support services provided by family, friends, statutory authorities and/or others for a mutual learning experience. Moreover, the BCODP was to provide personal assistants (P.A's) for all participants who were unable to bring their own.

Work on organising the Seminar began on April 1st 1992. But the whole of April and the first two weeks in May were spent looking for affordable accessible accommodation. The search for a suitable venue took so long because apart from one or two very expensive hotels and institutions especially for disabled people, the organisers could find no suitable conference facilities in the north of England with accessible residential accommodation for fifty disabled people and their P.A's.

In" view of this situation we reluctantly decided to hold the Seminar at Herewood College, Coventry -a college of further education specifically for disabled students. Apart from its segregative implications - a major concern for each of the organisers -Herewood has only 85 bedrooms. This effectively reduced the number of people able to attend the event. However, after protracted discussions with Herewood staff and a visit to the college the Seminar Support Group decided that the event would be held there on the 7th, 8th and 9th of August 1992.

As soon as the date and venue were fixed, the organisers set about publicising the event. It was imperative that as wide a media as possible should be reached if the event was to attract disabled people from marginalised minority group within the disabled community and young disabled people seeking to live independently. To this end appropriate advertisements were placed in the 'disability' press, mainstream 'care' journals, the women's and ethnic minority press as well as in the electronic media - radio and television.

Additionally, to reach disabled people using services provided by voluntary and statutory bodies who might not have direct access to the media, a letter and publicity leaflet were sent to a random sample of 95 relevant professionals in local authority social services departments, district health authorities, hospitals and residential homes.

Although we expected a high response to these initiatives, general enquiries far exceeded our expectations. They came from three main sources. Firstly, from people with physical impairments. In total, 92 application forms were issued only 17 were not returned. Given that participants satisfied the attendance criteria - P.A user or potential user with 'severe' physical impairments; it was agreed that two thirds of the attenders should be 'newcomers' -eligibility was determined on a first come, first served basis.

Completed application forms received when no places were left were forwarded to Paul Lindoe, the co-ordinator for the second event -scheduled to take place in November. This seminar would cater for people from southern England. Throughout these entire proceedings Paul was kept fully informed of our progress. All relevant data such as the minutes of Seminar Group meetings, application forms, publicity handouts, press contacts, P.A's addresses etc., were passed on as they became available.

Secondly, many disabled people unable to meet the eligibility criteria also wanted to attend the Seminar. In addition to non-P .A users, this included people who were currently using or hoped to use P.A's, but whose impairments precluded them from participation. Enquiries came from blind people, deaf people, and people with learning difficulties who had, rightly, interpreted the term P.A to include readers, facilitators, and advocates. Finally, several non-disabled professionals; ie. 'care' staff, occupational therapists, social workers, and a lecturer in further and higher education, also wanted to attend this event.

Great care was taken to ensure that the application form used would yield the information needed to accommodate participants' individual needs without it being oppressive or intrusive (see Appendix 3). Personal assistants were recruited from a variety of sources including personal contacts, the Spinal Injuries Association (SIA) and an advertisement placed in the disability press.

With Britain's inaccessible transport system, one of the biggest problems faced with organising an event of this nature is travel. About a third of the participants were to travel by train. Despite our formally contacting British Rail almost six weeks in advance, participants still encountered problems.

Due to the fact that Intercity trains can accommodate only one wheelchair user at a time, and the majority of participants were wheelchair users, many people were unable to choose which train they wished to use as the space was engaged. They were also unable to travel with each other.

One woman and her P.A could not get a seat on a train back to Scotland until Monday - consequently they had to spend an extra night in Coventry. Additionally, on the train home neither got their allotted seats for the entire journey.

In spite of the different arrival and departure times, we arranged accessible transport between the railway station at Coventry and Herewood College for all participants before and after the Seminar.

Once the event's agenda had been agreed, potential speakers were approached. It is notable that apart from the speaker from the Independent Living Fund (ILF), all the speakers were disabled people with a long history of involvement in the disability rights movement. They were each asked to talk for fifteen to twenty minutes on a subject of which they had particular knowledge and experience. Although the general content of talks was agreed beforehand, no-one was asked to provide a written summary in advance. Moreover, even though our budget did not enable us to offer a fee, all the speakers agreed to take part without hesitation.

Workshops were arranged to follow each talk. The composition of the workshops was structured to reflect the experience of participants; i.e. one third established P.A users and two thirds 'newcomers'.

Prior to the event each participant received a Seminar pack containing relevant maps, British Rail's travel leaflet for disabled travellers, background information on the disability rights movement (Appendix 1 and 2), data on publications relevant to self operated personal assistance schemes, a copy of 'The Personal Assistance Users Newsletter', a seminar timetable and agenda, and a list of participants.

One week after the Seminar all participants, excluding the cabaret, were sent a Seminar evaluation form (Appendix 5). Within a month twenty four of these forms had been returned representing almost a 50 per cent response rate. The general feeling among all participants was that the Seminar was an overwhelming success, and that there is an urgent need for more events of a similar nature, with more information about the disability movement and its activities. A preliminary evaluation report was immediately produced and circulated to members of the BCODP Independent Living Committee, the funding body, the Seminar Support Group and the Co-ordinator for the second Seminar.

Outline of the Report

This Report seeks to achieve broadly the same goals as those of the BCODP Independent Living Committee and the Seminar Support Group when organising this event; i.e., to develop further the principles of independent/integrated living and introduce 'newcomers' to self operated personal assistance use.

Hence, the first two articles provide a broad based introduction to independent/integrated living and personal assistance use. Stewart Bracking's piece provides a brief but informative overview of the emergence of the disabled people's independent/integrated living movement, whilst Maggie Davis presents a detailed historical analysis of the developments in personal assistance use.

The two contributions from Carl Ford and Richard Shaw provide a useful and practical guide for people wishing to set up and run their own personal assistance services. Deborah Kent, a Visiting Social Worker from the Independent Living Fund, provides an insight into the workings of the Fund.

The following three articles by Anne Rae, Nasa Begum, and Dennis Killin focus upon equal opportunities, independent living and personal assistance with respect to women, black people, disabled lesbians and disabled gay men. John Evans delivers a moving personal insight into the significance of Centres for Independent/Integrated Living and Networking in the development of the disability rights movement.

There follows a summary of discussions in the workshops which followed each key speaker. The summaries were taken from items listed on flip charts in workshop areas, notes taken by participants, and participants' comments derived from the returned evaluation forms. The section on Resources provides some useful updated information on publications and organisations with a particular relevance to independent/integrated living and self operated personal assistance schemes.

Apart from the contribution by Maggie Davis - which Maggie would have presented had she been able to attend the event - each of these articles is based on a talk given at the Seminar. They are presented in the order they appeared at the Seminar (Appendix 3) and not in a hierarchy of importance - each contribution is of equal importance.

2. An Introduction to the Idea of Independent Integrated Living

A Brief Overview

Stewart Bracking

Until not too long ago one of the most important features of being a disabled person was the near certainty that we would not be allowed to live independently. Environments were constructed without reference to our needs and disabled people were denied the right to live in the community. Also, we were not expected to demand the same rights as non-disabled people.

For many of us it was not until the 1980's and 1990's that the idea of independent living became more than just a dream. Over the last few years more and more disabled people have been able to live independently. Hopefully, in the future, many more disabled people will be able to enjoy that right with more conferences like this one, where disabled people can learn and share their skills, making it a distinct possibility.

It is important to remember that the idea of independent living for disabled people as a right has evolved from within the disability rights movement -and not from within able-bodied society. To date, professionals' vested interests and public ignorance - or to be more accurate, discrimination -have been major obstacles in our struggle for rights.

Discrimination against disabled people can be traced back at least as far as the nineteenth century with the Poor Laws and the spread of institutions and workhouses. Victorian society was synonymous with the widespread segregation of disabled people into such places. Many of the charities which flourish today have their roots in this period.

It was not until the post war (1939 -1945) years that things began to change for disabled people. In the late 1950's and early 60's disabled people began to challenge the whole idea of institutional 'care'. In the 70's they began to leave institutions in increasingly large numbers and develop support systems of their own within the community.

Similar developments were happening overseas too -specifically in Scandinavia and in the USA. America during the 1970's is especially important because of the nationwide growth of Centres for Independent Living (CIL's). The CIL's were important because they showed conclusively that disabled people could run their own support services themselves. Until then no-one believed that disabled people were capable of taking control of their own lives and living within the community in the same way as everyone else.

In the 1980's the demand for independent living increased. Centres for Independent Living were established in Britain and disabled people developed the idea of self operated personal assistance schemes. At the same time disabled people became better organised both nationally and internationally.

In 1981, during the United Nations' 'International Year of Disabled People', Disabled Peoples' International (DPI) was formed. This is the only international umbrella organisation for organisations controlled and run by disabled people.

In the same year the British Council of Organisations of Disabled People (BCODP) -Britain's equivalent of the DPI - came into existence. A member of DPI from the beginning, the BCODP originally had only a handful of member organisations. These included the Disablement Income Group (DIG), Sisters Against Disability (SAD), the Spinal Injuries Association (SIA) and the Union of the Physically Impaired Against Segregation (UPIAS).

Today, the BCODP has 95 member organisations controlled and run by disabled people representing over 300,000 individuals. The BCODP is the national representative voice of the disability rights movement in Britain and it has been at the centre of the struggle for independent living and self operated personal assistance schemes throughout its eleven year history.

It is hardly surprising that these developments had an effect on Britain's welfare services and charities. Local authorities have expanded community based services such as home helps. Using the Scandinavian 'Fokus' system as a model some housing associations have started to construct small numbers of accessible houses and flats and charities like the Community Service Volunteers (CSV), have set up community based support systems. There is an important difference between their approach and that of the disability rights movement. Local authorities, health authorities and charities tend not to see independent living as a basic human right as we do. For them independent living is still a 'welfare' issue.

With few exceptions local authorities and charities still see disability as basically a medical problem - disabled people and their impairments are the problem - not the disabling society in which disabled people have to live. For them the emphasis is on the functional aspects of independent living. This means dressing, cooking, eating, washing etc. The kind of things able-bodied children get taught in domestic science classes in mainstream schools. These considerations are still the main focus for local authority social services departments, health authorities, social workers, and charities.

While such things are obviously important they have to be seen in relation to other equally important issues, such as an accessible house or flat, accessible transport, accessible schools, employment, and, most importantly, the money to buy and control the services we need. In many ways, if disabled people had the same rights and opportunities as non-disabled people, then the issue of independent living would not have the same significance as it does today.

For me this is the crucial difference between their view of independent living and ours. Independent living is more than just living outside an institution it is about rights -equal rights and opportunities for all disabled people. It is about the complete integration and inclusion of disabled people into all aspects of society. The struggle for self operated personal assistance schemes is one part of that struggle.

It is important to remember that self operated personal assistance schemes are but one solution to the problem of living independently. There are others, as the Derbyshire Coalition of Disabled People (DCDP) and others have shown. What is important is that disabled people have the right to choose. Independent living is about choice and control, it is not about doing everything by yourself. Nobody - whether they have an impairment or not -can do everything themselves.

When disabled people use P.A's it does not mean that they are dependent on others. If a P.A has to push a wheelchair, help a disabled person dress or reach for a book, it should be seen as enhancing the disabled persons ability to live independently. The important element is whether the disabled person has the right to say 'no', to hire and fire at will, and to control payments.

At present disabled people are prevented from living independently within the community because society continues to ignore our needs and denies us equal rights and opportunities.

An inaccessible environment, poverty, and essential services controlled and run by non-disabled people prevent us from living independently. Independent living is about access; access to schools, jobs, transport, houses, public buildings and leisure etc. -all the things that non-disabled people take for granted -and about disabled people having control of the services they need.

These are basic human rights that still have to be won. Over the last few years disabled people and their organisations have intensified the struggle for disabled people's rights with the campaign for anti-discrimination legislation. This seminar is a major part of that struggle.

Personal Assistance -Notes on the Historic

Maggie Davis

Many of the ideas which currently cluster together under the banner of 'independent living' have been part and parcel of the struggles and aspirations of individual disabled people, probably as long as disabled people have dreamed of freedom and independence. A central element of 'independent living' is personal assistance and, in particular, having direct access to the cash which gives freedom to hire and fire assistants who carry out duties determined by and under the control of the disabled person him or herself.

It is sometimes overlooked that, in the same way that the British disabled people's movement has a long history of growth -since at least the 1890's -so too has the development of ideas around the notion of 'independent living' and personal assistance. Certainly in Britain, as elsewhere in the world, these ideas came out of the experiences of many early pioneers, whose struggles were more directed to 'living independently' than to 'independent living'.

Unlike the United States, in post (1939-1945) war Britain, disabled people's aspirations of living independently have had to be fought for on at least two fronts. There was in both cases of course the shared struggle for practical resources and attitudinal support in the community. However in Britain, as in some other countries, disabled people have had in addition to overcome the obstructions, anomalies and vested interests of a well-established welfare state.

These welfare barriers to independent living can be traced back in the British Poor Laws to well before the famous, "43rd Elizabeth of 1601," (legislation) and this in itself indicates how deep rooted the vested interests in welfare really are. These Poor Laws were always associated with the practice of giving what was called 'outdoor relief' which, as an idea, can be imagined as a precursor to direct payments. However, this system and the bill attached to it through the poor rates, eventually came under strong attack. The new Poor Law of 1834 attempted to put paid to it altogether, by replacing it via the harsh corrective regime of the workhouse.

Victorian society may have extolled the virtues of hard work, thriftiness and sturdy independence -but was clearly not interested in doing anything about the proliferation of social barriers which prevented disabled people's participation

in the same value system. Instead, it reinforced the picture of workhouses and institutions as the proper place for people who couldn't support themselves. Coupled with public hostility to vagrancy and mendacity, this climate stifled the kind of social developments which could have supported disabled people's independence and participation.

The proliferating number of Charities took the same values on board. For example, John Groom's may espouse independent living today, but it started in the 1860's as 'John Groom's Crippleage and Flower Girls Mission'. Later, the increasing role of the state adopted the same values and assumptions. After World War II, as part of the modern welfare state, the 1948 National Assistance Act was supposed to replace the Poor Law but Section 29 merely introduced a new wave of institutions.

Against this background, tough-minded individualism was the only choice for disabled people who had no family or who wished to live independently of family. The multitude of barriers and disincentives that existed, however, made 'living independently' a more realistic description of what actually happened in the lives of these pioneers, than the notion of 'independent living'. The difference can be summed up by the necessity on the part of those individuals involved to perform the maximum number of tasks without help rather than the maximisation of choices with assistance.

Clearly, at this point in time, the name of the game was survival -for many, survival on a knife edge, where a mistake could land you straight back in the institution. New thinking and a fresh use of resources was badly needed. A change in the prevailing climate came with the questioning by disabled people of the role of institutions. One of the most significant challenges came during the 1960's, with the struggle to liberalise the 'Le Court' Cheshire home in Hampshire led by Paul Hunt. This influence lay in the background of moves in the 70's by residents of Le Court to set up 'Project 81' and, a few years later, the Hampshire Centre for Independent Living (HCIL). Other struggles to reform institutions also took place at the 'Ludwig Guttman Hostel' at Stoke Mandeville, at the 'Pearce House' YDU in Essex and at 'Cressy Fields' Part III institution in Derbyshire.

There were many graphic examples of disabled people's struggles to live independently. I can personally recall being encouraged by people like Pamela La Fane, Joan Dawe, Yvonne and John Hall, Jack and Margaret Wymer and others who escaped the all-embracing clutches of a variety of state run or charitable institutions. Together with many more courageous, tenacious and

inspiring individuals they helped change the prevailing climate of ideas so that now, disabled people see themselves differently.

It was the efforts of such people which led, in the late 1960's and throughout the 70s, to significant shifts of attitudes in both the state and in the charities. However, some developments, for example, that involved the 'responauts' from St Thomas Hospital, were so successful that future progress was halted. In that case, people using respirators, hiring their own help at home with special DHSS money made it clear that existing welfare provision and institutions were inappropriate. To develop this kind of policy more widely could obviously have had serious repercussions for the 'disability' industry.

These developments linked up with news of the Swedish 'Fokus' housing schemes, Danish 'Collectivhaus' and the 'Het Dorp' development in Holland. Events in Berkeley, California and across America (see John Evans paper) began to influence developments in the United Kingdom. The charities in particular began to protect their own controlling influences in disability affairs by adjusting and adapting to the changes that disabled people had set in motion.

For example, the Spastics Society tried a version of the 'Fokus' system at Neath Hill in Milton Keynes; the Habinteg Housing Association started building houses with limited support services; the Leonard Cheshire Foundation set up flats with some person~l assistance services at Tulse Hill and started their home care service; and the Crossroads Care Attendant schemes came about on the initiative of a disabled person called Noel Crane.

At the same time disabled people began to look for a more structured approach, one built much more closely on the direct experience and under the control of disabled people themselves. In 1972 Delia Dudgeon organised a well attended conference in London for disabled people with a view to stimulating well-designed housing for disabled people seeking to live independently of their families. In the mid 1970's Brian Lewis was proposing a commune as an alternative to institutions and set up a Housing Co-operative to bring about better community based housing for disabled people.

About the same time, with my partner Ken Davis, the Grove Road scheme was set up as yet another approach to securing more choice and control in disabled people's lives. This was a collective approach to meeting a number of identified needs including information, peer counselling and support, good housing

design, appropriate technical aids as well as personal assistance. Similar schemes followed in Edinburgh, Rochdale and Gillingham.

Sheltered Housing for the Disabled (SHAD) in Wandsworth looked at the use of voluntary helpers in the community and 22 main street, Newton, was another collective approach to hiring and organising personal assistance. Each of these initiatives helped to reinforce the notion that disabled people could and should live in the community rather than in an institution, and that the resources should be available to permit this development.

During the 1980's the expansion of the disabled people's movement stimulated a further growth of ideas, backed by the collective strength of its members. The sheer necessity for people to 'live independently' began to be replaced as new opportunities for funding personal assistance were conceded, such as the use of 'flexible budgets' by local authorities and, more significantly by the Independent Living Fund (ILF). The latter gave a boost to those promoting the kind of individualistic approach to personal assistance pioneered by the American Independent Living Movement and favoured by HCIL.

Groups such as the Derbyshire Coalition of Disabled People (DCDP), whilst supporting the drive for a more committed approach on the part of the Government for direct payments -particularly since the ILF came under threat - sees this approach as being just one element in a spectrum of arrangements which offer a wide range of disabled people more choice and control in the availability of personal assistance. Through the Derbyshire Centre for Integrated Living (DCIL) it has also worked to set the need for personal assistance squarely within the context of other essential needs. In this way, it tries to ensure that the personal assistance issue is not used as a political device simply to replace care with cash -and as a means to conveniently dodge the wider social responsibility to remove the many other social barriers which prevent disabled people as a group to secure equal rights and opportunities.

3. 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 on 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).

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 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.

Personal assistance schemes can also be paid for by a joint finance pack. This is money from a combination of Sources such as the Local Authority, District Health Authority and a person's benefits. Attendance Allowance, Disability Living Allowance, Severe Disablement Premium or Invalid C Allowance can also be used to help pay for personal assistance -although recognise that these benefits may be needed for other disability related costs.

Organisations like the Derbyshire Centre for Integrated Living (DCIJ) Hampshire Centre for Independent Living (HCIL), the Spinal Injury Association (SIA) or Greenwich Association of Disabled People (GAD) with expertise in this field can provide help and advice with funding packages a applications -their addresses are shown on page 69.

Job Descriptions

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).

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).

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 college 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 organisation to receive the applications on their behalf. Some of these organisations have 'Pay and Display' boards -here the charge is about 50 pence.

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).

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). 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.

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 for tax arrears or from the Contributions Agency for unpaid National Insurance Contributions.

In terms of current schemes 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 P A YE schemes can either be operated on a 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 pay roll schemes are:

For the 'Simplified Deduction Scheme' ask for 'P4Q 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' (PA YE) you need a P4 'Starter Pack' from the Inland Revenue Office. Also ask for a copy of the 'Employer's Guide to PA YE'.

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 a 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 P.A 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 PA 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). 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.

4. 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 are less likely to be problems.

It is important that both the disabled person and the P.A's 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 kind 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 event 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 are 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's 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 had 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 users 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. We as disabled people 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 remember that at this point in time the job of P.A is not well recognised and does not have the status of other comparable occupations. We, as disabled people, should take every opportunity to resolve this situation and try to give the work the status it deserves.

Example 1

Personal Care Assistance 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? |

Non-Domestic Needs

- | | |
|-------------------------------|-------------------------------|
| Employment | - Routine? |
| Study | - Number of days per week? |
| Visiting friends or 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 need 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 are and to always listen to the requests and the directions given.

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 incontinence management. Assisting in maintaining a bowel and bladder routine. Fitting and attention to condom drainage system. Assistance with 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 cooking of meals.

General housework, including the cleaning and dusting of rooms, furniture, fittings 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; ie, clearance of snow from paths, cleaning windows etc.

Upkeep and maintenance of equipment; ie, 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 Assistant's 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

immediately. 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 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 assistant's 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 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 weight 10 stone. Anyone of 5 foot 2 inches and 8 stone 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 occasion 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 Aalborg in Denmark, it has good shops, 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 deducted accordingly.

Example 4

An Application Form

Because of 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. Married/single/other
6. Nationality
7. Religion 8. Do you smoke?
9. Number and ages of any dependent children
10. Do you hold a current driving licence?
11. Details of any convictions or endorsements
.....
12. Do you have your own transport?
13. How would you travel to work?
14. Are you willing to work some weekends?

15. Are you willing to 'sleep in' occasionally?

16. Details of any experience of residential or care work?

.....
.....

17. Do you mind animals?

18. Any hobbies or special interests?

19. Educational qualifications.

20. Why are you applying for this job?

.....

21. Please give details of previous employment history:

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

.....
-------	-------	-------

.....
-------	-------	-------

.....
-------	-------	-------

22. Name and Address of two Referees

1

2

23. When would you be able to start?

.....

24. Any additional information relevant to this application.

.....

.....

25. 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 Married/Single/Other

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 of 3/6/9/ months?

.....

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				
Mon					
Tue					
Wed					
Thu					
Fri					
Sat					
Sun					

WORK SHEET.

Name: _____

Date	Time	Rate	Earnings
		£	
		£	
		£	
		£	
		£	
		£	
Total			

5. Financing Personal Assistance and the Independent Living Fund

I have been a visiting social worker for the Independent Living Fund (ILF) since June 1991. I am also a local authority social worker working for the General Services Team at East Birmingham Hospital and a trained nurse, so I have some experience of providing personal care. I have also been appointed to the Disability Appeals Tribunal - but as some of you will know the Tribunal has not actually sat yet.

I would like to tell you a little bit about the ILF and then I will be happy to answer any questions. I must say that I might not be able to answer all your questions because as you know, the future of the ILF is now uncertain.

Originally the ILF was launched in June 1988. It was set up to plug the gap left by the abolition of the supplementary benefit system after the 1988 Social Security Reforms. Following the Reforms there was nothing to replace the Domestic Assistance Addition which helped some people pay for domestic care. Nationwide, there were about 600 people claiming this particular Benefit.

The ILF was set up as a temporary measure until 1993 - when new provision, introduced under the 1990 Community Care legislation, will take over. At the beginning it was envisaged that there would be only a small number of applications to the Fund - maybe somewhere in the region of 600 - although the scope would cover both personal and domestic care. But in fact it has taken off in a phenomenal way. I think in the first year alone there was something like 5000 applications. Currently about 1450 people are getting help from the ILF.

As you can imagine there were quite significant funding problems right from the start. Quite simply the Government had not put enough money into the Fund. As a result, there have been all sorts of problems with lists being closed and suspensions being made. The ILF's 1992/93 budget is £97 million.

The ILF is a discretionary charitable trust financed by the Government and governed by an independent board of trustees. It is a strange sort of animal really - most people cannot understand the logic of why it was set up in this way.

With regard to the question of who is eligible for help from the fund. To apply to the ILF people have to be over the age of 16. They have to be in receipt of the higher rate of Attendance Allowance - or the higher rate of Disability Living Allowance, which is currently £43.55 - and they must be unable to pay for their care needs themselves. People with savings of over £8000 are not able to claim from the Fund.

The Fund can contribute toward the cost of personal care, but when we talk about personal care we have to be quite specific about what that means. It means very nitty gritty basic care and day to day personal needs. Items of need which are labelled 'social interaction' or 'medical needs' - going out socially or physiotherapy, for example - are not eligible for support by the Fund.

Although, as a visiting social worker, I have learned that most disabled people need personal care at the same time as other activities, for example, when they are getting out and about: So such criteria need not necessarily bar people from getting support for care from the Fund.

In exceptional circumstances there is a facility for people to actually get funding for specific pieces of equipment, but applications are quite difficult to argue through. The application has to be for items that can be seen to have a saving for the Fund. One of the best examples is a turning bed which in certain circumstances can eliminate the need for 24 hour care or a night worker. As you can see the criteria is quite tight.

When an application is received by the Fund basic things are looked at by ILF staff. If they are satisfied that it meets the Fund's criteria it is allocated to a visiting social worker in the locality. The visiting social worker dealing with the application will then arrange to meet the applicant.

It is very important that we meet the actual applicant. We often find that other members of the family will say 'It would be better if you see me, I can tell you about the person's needs' , but we really have to make it clear that we do have to meet the actual applicant. We have to find out what THEY want; we have to elicit as much information from them as possible. That is not to say that we do not talk to other members of the family but the applicant's needs take priority.

There is also provision for applications to be dealt with quickly. One of the biggest complaints people have is that it takes a long time for an offer to be made. It may not take a long time for somebody to be visited by a visiting social worker but currently it is taking about ten to twelve weeks for the assessment to go through, and for the payments to start being made. That is an awfully long time and we do appreciate that this is a problem for some people.

If there are urgent situations, for example, if the applicant is terminally ill, then we are able to do assessments fairly quickly -usually within a week or two weeks at the outside.

The purpose of the visiting social worker is to ascertain the care needs of the applicant or to help the person look at what their care needs really are. Quite often the applicant is actually getting a service from the local authority. Some people are happy with that service and they just want help to supplement it.

Other people use these services because they do not have a choice. In this type of situation we are able to help them have a choice. If people do not want local authority services -where they do not know who the carer is or where they have to get up at specified times or go to bed at 6.00 pm, these are bad examples but I have come across them -then we can ask the Fund to ignore these services. It is about giving people a choice.

However, we do have to be careful that the Fund should not be seen to be taking over from local authority services.

The recommendations in the report should give in hours per week the amount of help the Fund should be supporting. This is a figure worked out by the visiting social worker and the applicant. It is a figure that both should feel happy with and a figure that covers all care needs. It can cover night care, from one to seven nights a week -whatever is appropriate.

There is also a summary made of all the information that is contained in the assessment. This should show very succinctly what is required and what is recommended. The report is then looked at by ILF staff and they decide what financial help can be given.

There are financial considerations which are taken into account -for example, any income in access of income support. As a visiting social worker, I am not involved in the final decision which is worked out on a fairly technical basis.

Fund staff will usually come up with a weekly amount of money that the Fund can provide. That money is then paid on a four weekly basis by credit transfer , directly into the applicant's bank account, so that they can withdraw it and pay their carer as required.

For actual payments there are three bands: inner London, the South, and anywhere else in the United Kingdom -roughly, anywhere from Watford upwards. In this particular area, the West Midlands, the Fund base their funding on £3.75 per hour. The night rate is £26.50 an hour, but there is an upper weekly limit and that is £450 per week.

The other thing to consider is that there can be various things taken off that offer. If the claimant is getting Severe Disability Premium then the figure will be reduced accordingly. This is because the Fund considers that this payment should be used to pay for care. If someone gets the Special Transitional Addition then that will be taken into account as well.

Since March 1992 Attendance Allowance will also be taken into account. The reason for this is that there is such a great demand for ILF money that the Fund holders have had to look at ways to increase the amount they have available. So now half the Attendance Allowance, £21.50, is taken into consideration.

So all those factors will be considered and a letter will go to the applicant stating 'we are prepared to make a contribution of up to £X per week'.

There is flexibility in terms of how that money is spent. To some extent the assessment is only a guide-line. If a client can buy in care which costs less than the hourly amount we allow, then they have the option of buying in more care.

I often find when visiting people that they can underestimate the amount of care they need. In such circumstances it is perfectly possible to go back to the Fund and ask for more help. I think the Fund accepts that for some people care needs are going to increase rather than decrease.

With regard to the future of the Fund, really do not know what is going to happen. I have talked to the people in Nottingham (ILF offices) and they do not know either. We have been assured that people who get help before the closing date for applications, March 1993, will continue to receive support from the new body, but the situation for new applications is unclear.

The Government say that they are committed to continue support but how it is to be distributed we just do not know.

A Selection of Questions from the floor.

Q. At present, can you apply for money to set up a new home when leaving a residential home?

A Yes it is possible to apply to the Fund for that sort of help.

Q. For someone moving out of residential care what is the fund willing to pay for?

A. The Fund can and will pay for personal assistance. It cannot pay for the nuts and bolts of putting your home together.

Q. I am blind and have epilepsy and I do not actually need personal care, but I do need help with certain things like correspondence and supervision at certain times of the day. Can I claim for that supervision from the ILF?

A. There is a fine line between supervision and personal care. Now the Fund's policy is quite clear, it does not pay for supervision, but in certain cases we (visiting social workers) have been able to argue that assistance is needed for things like getting from A to B and dealing with correspondence can come within the boundary of personal care.

Q. Does that mean then that I can claim for someone who is living with me, someone who acts as my personal assistant occasionally?

A. It is possible for members of the family to be paid as carers but it cannot be close members of the family or relatives living in the same household.

Q. What is the situation where an individual has more than the £8000 limit in resources -some of which is set aside for disability related costs -and wants to apply to the ILF for support?

A. If that person has say £10000 in the bank and £2500 is to be spent on putting a lift into their home then that would be taken into consideration by the Fund. It would not jeopardise their application in any way. However, the Fund would have to be satisfied that the money would be spent in the very near future.

Q. Will the Fund help with mobility needs?

A. Mobility is something the Fund will not help you with.

Q. What about the situation where someone has more than £8000 in savings but some of it has been put aside to buy a car , would they be eligible to claim?

A. If the car is a specially adapted vehicle, then an application would be considered.

Q. What about money for an electric wheelchair?

A. No we cannot help with that.

Q. Once you are receiving support how is it monitored? Do you have to be assessed every year?

A. Well they do not send out a visiting social worker every year. They do tend to reassess in terms of a questionnaire; it is an audit rather than a reassessment. The Fund's auditors also review a cross section of people. The times when people are visited is if the applicant has said that their care needs have increased, this has to be considerable. There are times when if an applicant asks for another five hours a week support then the Fund holders may say yes without a reassessment.

There are occasions when a reassessment is needed -when say a partner has left. That would be seen as an emergency and an assessment needed.

Q. Given the current uncertainty at the ILF, what is the situation for people who are actually receiving funding but whose care needs have increased substantially and who may need more support?

A. Well as I said people currently receiving support are safe and we are given to believe reassessment for those people will not be a problem. Although I cannot say for sure, it will almost certainly depend on the new budget -we are all in the dark at the moment.

Note:

Because of increased demand and the need to process all new applications before the end of March 1993 the ILF had to close to all new applicants on November 25 1992.

At the time of writing (February 1993) it is being replaced by two funding organisations :

- i. 'The Independent Living (Extension) Fund' will deal with people already receiving financial support but it will not accept new applications:
- ii. New applicants must apply to the 'Independent Living (1993) Fund' -but at present the criteria for eligibility is unclear. However, according to Nicholas Scott, The Minister for Disabled People:

'The new fund for this group will work in partnership with local authorities, reflecting their primary role following the April 1993 community care changes. The local authority will be expected to make a contribution by way of services equivalent to what it would have spent on residential or nursing care and the fund will be able to provide a cash payment in addition' .

6. Equal Opportunities, Independent Living and Personal Assistance

Independent Living, Personal Assistance a

Anne Rae

I want to raise a number of important issues which need to be on the agenda when we think about women, independence, and personal assistance. These are issues which need a lot more discussion -maybe in a different arena. I would have liked to talk to women only but, sadly, it's not possible this weekend.

The central contradiction for women as personal assistance users is that traditionally we are seen as 'the carers' and disabled women are not excused from that role except when it suits society. Some of the things that we have been talking about today make it very clear that society would like to exclude us from motherhood -especially if we are likely to produce physically or intellectually impaired children.

When it comes to providing 'care' , because women are expected to do it and because there are so few people doing it, disabled women are expected to do it in the same way as everybody else. The trouble is that when we need personal support systems ourselves, the system is reversed in some mysterious way. There is a very real discrimination against disabled women when it comes to the assessment of 'care' needs .

Part of the Independent Living Movement is about addressing how the assessment system works. For instance, in the Home Help Service women know that from the start perceived need will be instantly recognised for men, but at the very first approach -usually over the telephone -we are confronted with the question 'Well you've been managing so far why do you want one now'? And then someone will come down to see you -with a clipboard. Then the problems really start. If you can walk then God help you, because if you can walk you can push a Hoover, and you don't need a home help.

If you're actually living with somebody then that's even worse. If you're living with a woman then it's assumed there isn't a problem, because you can 'share' the chores or she can look after you. If it's a man you're living with, if he's a disabled person, then you have obviously been supporting him -unless there's evidence to the contrary. If he's non-disabled then he can support you.

Either way you, as a disabled woman, you do not need personal assistance.

I think I can illustrate the extent of discrimination experienced by women most easily by telling you about a man who used to live in my road in London. His wife died giving birth to their eighth child and he absolutely refused to give up work. He also refused to let the children go into care. So, naturally, all the appropriate social services were geared up to support him and his children in their home.

Now there is no way that a woman -disabled or otherwise -could have made those demands. If a woman in that situation had said that she was going out to work and that social services should look after her children then there would have been a public outrage. It is these kind of traditional oppressions which affect disabled women in a far more subtle way.

In assessments, as disabled women asking for support, we have to explain our impairments and we have to explain our inabilities. As disabled women we have to humiliate ourselves in a way in which all women in this room will understand -especially when we are asking for personal and domestic services such as home helps.

In most cases disabled men don't have to go through these hoops to get personal assistance services. It's a much easier transition from self care to supported care for a disabled male.

I would like to quote a woman here today who quite jokingly said to me 'well my husband's at home and there's a woman looking after him -but if I was at home nobody would come round' .For me that statement carries such a kernel of truth. I don't know what the answer is but the disability movement has really got to keep the political issues surrounding the idea of independent living for disabled women in mind.

Men and women often seem to have a startlingly different perception of what personal assistance might be. Men are almost always looking at buying several hours of personal assistance per day, with very little regard to technical aids and house adaptations, whilst women want much less 'person' time. This again works against us as the financial structure of the Independent Living Fund (ILF) and Attendance Allowance (AA) have been based on the assumption that 'severe impairment' equals constant attendance.

Women are saying that they do not want what they do not need but cannot get what they do need. It is a strange situation when we may get financed for 24 hours personal assistance but not for 4 hours.

The other thing that needs to be considered seriously when thinking of personal assistance and disabled women is the choice of personal assistant (P.A). As we know, traditionally women are expected to take the role of 'carer' or personal assistant (P .A), but there is the problem of the social implications of being with an able-bodied woman as a disabled woman. Although there are some male P.A's, for a disabled woman to have a man as PA raises a number of questions which many disabled women find difficult to deal with. Again, this is not as great an issue for a disabled man.

We touched on this in our workshop because some of us recognised that able-bodied women can easily diminish what little sexuality we as disabled women are perceived to have. As all disabled women who are socially active know only too well, p .A or not, if you're in a social situation where able-bodied women are around you get shadowed in to a total non-existence. I don't think any of us were bitter around this, but it's something that we just have to learn to live with. Having said that, it's not a good way for us to have to live; we are asserting our sexuality and being proud of it now. But our struggle against the stereotypical images of sexually attractive womanhood goes on and on.

'Care' is an 'F' word to both sexes of disabled people, but women in this situation are having both their impairment and their inadequacy as women confirmed -quite severely confirmed because we need' care' and we are the traditional carers .

It is very difficult for a disabled woman when she has a partner who is a disabled man and she can no longer support him. If I can revert from the political to the personal to illustrate the point, I had such a relationship that really came to grief when I could no longer physically support the man I was living with. He was lucky and got funded by the ILF (Independent Living Fund) and got into the P.A system and suddenly I was redundant.

It was so exciting for him after sixteen years to have all these new young attractive woman in attendance on him. I was relegated to the background completely.

Although I've got over it now I wasn't too pleased at the time. While all relationships coming to an end are difficult, many disabled women with similar experiences also find that their partner's P.A undermined their authority, their assistance, and their sexuality.

Another thing which I think ought to be mentioned and which my dear friend Maggie Davis (a P.A user and member of the Seminar Advisory Group) who, sadly, could not be with us -would want me to mention is the issue of who controls who in the user/personal assistance relationship. We are very concerned that in this relationship -a very new structure for all of us -that disabled women and disabled men do not abuse P.A's. Both Maggie and I feel too that the relationship has to be built on equality and mutual respect; however hard that is to achieve I think it is something that we all need to strive for.

The American model is hire and fire. When problems come up in the P.A relationship, which they often do, you don't work through the situation with the P.A you get rid of them. I think that this reflects the harsh attitudes of an able-bodied male dominated society. I think that it's something that disabled women and disabled people in general should think very carefully about and not want to emulate.

Lastly, I would just like to remind us all the able-bodied world works on a balance sheet where friendships and support systems operate on a kind of debit and credit basis. The main problem for disabled women and all disabled people in the kind of support systems normally available is that we don't have the kind of bargaining power that non-disabled people do. I think that we have to think about how we can bring to the P.A relationship some support for P.A's when we see the need. I think what hurts lots of disabled people is our supposed inability to support non-disabled people who sometimes need our help. I think once we get into this highly sophisticated system of personal assistance, then we can really start working out truly equitable relationships which make both disabled and non-disabled people feel good.

Independent Living, Personal Assistance and Black Disabled People

Nasa Begum

My brief was to speak about how personal assistance and independent living affects disabled black and minority ethnic people. I shall use the term black to refer to all people who are not white. I recognise that some minority ethnic people may not identify themselves as black, however it is a term used widely to represent the political struggle against racism.

What are we actually talking about when we talk about independent living and personal assistance? independent living pivots on the right to control our lives without being oppressed, intimidated or abused in any way. CONTROL is the central component of independent living.

Many of us as disabled people have experienced oppression, intimidation and abuse in institutions and in society generally. The issue for black disabled people is the fact that our oppression has been compounded by the fact that we have been encouraged to ignore our blackness. People think that if you just focus on our concerns as disabled people then all our needs will be met.

Alternatively, if people are feeling really generous then perhaps catering for a different diet or linguistic needs will mean that the 'ethnic equal opportunities issue' has been dealt with.

I am sorry to disappoint you, but the issues facing black disabled people, like disabled women, disabled lesbians and disabled gay men, are part of the main agenda and cannot be simply tagged on as a tokenistic equal opportunities issue.

As a black disabled woman I cannot separate different aspects of my identity into separate neat compartments. My experience, concerns and requirements are shaped by my collective experience of race, disability and gender. Of course there are times when certain things seem more important than others, ie. when another disabled person tells me I would be lucky to get home helps in the country I come from, then I know it is racism that is my concern at that point in time.

Similarly, if a personal assistant is answering questions on my behalf when I am meeting with someone, then I know it is disablism that is important to me. In reality it is not always easy to distinguish when racism starts and disablism starts. For example, in the latter situation the P.A may think that as an asian woman who does not appear very 'westernised ' perhaps I do not understand the questions?

We are black disabled women and men who belong to many different sections of society and we must be recognised and valued with our entire identities.

Lots of black disabled people who have been so encouraged to focus only on disability seem to think that the fact that they are black does not matter. Implicitly or explicitly, they have internalised the racism that has confronted them. The effects of this can be so overwhelming that many of them withdraw from the public sector, from the disabled community, and from everywhere else where they may encounter racism.

I have heard a lot of people say that it is all right for black disabled people because we have the Race Relations Act, and also we have got lots of family somewhere. It is hideous, as a black disabled person the Race Relations Act does nothing for me. It does very little for anybody actually, but it certainly does nothing for black disabled people. We have specific concerns because of our impairments and we have specific concerns because of our race. Often they cannot and should not be separated. Like the Sex Relations Laws do nothing for disabled women so the Race Relations Act does not prevent discrimination against black disabled people.

Living with family members and independent living are usually considered opposite ends of the same pole. For lots and lots of black disabled people there is not a choice. If you live in a society that is racist, in a community that will not acknowledge your needs as a black disabled person, how can you exert a positive choice?

If you need particular things to enable you to live your life, and those things are not being provided, then how can you exert a positive choice to have independent living and acquire personal assistance?

Some black disabled people like other disabled people may want to live with their families, but that comes at a cost and compromise. There are lots of black disabled people who would want to take up the option of independent living and personal assistance if the resources were available and if there was a community that actually supported them and actually acknowledged some of the issues that affect black disabled people.

Black disabled people do not want to have to be compromised in terms of what we need.

There are practical issues around food, around clothes, around religious and cultural practices, and around language that make the whole question of personal assistance especially difficult for us. Never scapegoat black disabled people by saying 'well it's just because they've got different cultures, different religions, they've got too many demands because they won't eat western food...'

If we are talking about independent living we should have the right to eat what we want, when we want, how we want, and with whoever we want.

One thing that I would like to briefly mention concerns issues around safety. Abuse is an issue that's confronted by lots of disabled people within personal assistance relationships - abuses on many levels. It can be something as simple as not being able to have what you want to eat and the control of that situation or it can be about domestic violence. It can be about assault and it can be about racism- blatant racism. I think when developing a check-list for ensuring safety in the user/personal assistance relationship we need to think of some of those Issues.

What do you actually do if your P.A is blatantly racist? - when you need to get in the bath, or when you need to go somewhere. Those sort of parallels can be drawn everywhere. Black disabled people should not have to be dealing with these situations.

Practically, it is very difficult for black disabled people to get P.A's. I think that we need to do a lot more work with the non-disabled community to tell them what we mean by personal assistance. We need to actually talk to the black community and to the lesbian and gay community -and to other communities -to ensure that there are sufficient P.A's available for the different groups of disabled people.

Another issue that I want to raise while we are on the subject of black P.A's. I think a question that needs to be thought about concerns power relationships. There are a lot of black women in the labour market. They are a cheap pool of labour. So what do we do when white disabled people are employing black people as P.A's. I am not saying that they should not, but I think it is an issue that needs to be thought about very carefully when considering employer/employee relationships.

Organisations of disabled people and Centres of Independent/Integrated Living (CIL's) need to start addressing these issues, because if the organisers of these structures haven't considered subjects like control, identity, racism, abuse, sexism and violence then how can they support disabled people dealing with some of those things. The user/personal assistant relationship is an incredibly intimate one, and black disabled people -and all disabled people -need to know that they can get the best quality service when they need it.

Independent Living, Personal Assistance, Disabled Lesbians and Disabled Gay Men

Dennis Killin

What is independent living? Is it only to do with where we live and what we eat, or is to do with the very quality of our lives as disabled people? These are just some of the important questions that those of us who want to live independently have to deal with. When moving away from home or from an institution, making decisions about where to sleep and what to eat can pose real problems for disabled people - for many, decision making itself can be a real challenge.

One of the biggest challenges all disabled people have to face when living independently is how to negotiate relationships - whether with personal assistants (P.A's), friends or potential lovers. Here the word 'lover' refers to all types of sexual relationships -not just heterosexual ones.

In terms of sexuality, disabled people are no different to non-disabled people. Coming to terms with one's sexual identity -whether it be heterosexual, lesbian, gay or bisexual -can be a very complicated and difficult process. It raises a number of complex issues which need to be considered, especially by personal assistance users.

The issues for disabled lesbians and disabled gay men are very similar to those already raised. How does a person who moves out into the community set about setting up personal assistance support systems -particularly if they are unsure of their sexual identity.

As we all know many disabled people -never really get the opportunity to do so is also a problem for many young disabled people living in a home environment where the well meaning 'care' provided by other family members is so overpowering that the issue of sex never comes up.

Once a person moves out into the community and starts thinking about independent living and personal assistance they also have to consider other aspects of their life; and sooner or later they have to start thinking about how to develop their personal sexuality. At some point they have to decide what that sexuality might be.

Once a sexual identity has been decided upon the question of equal opportunities becomes important -particularly when recruiting a P.A. If you set the remit of the job description and the expectations of your P.A too narrowly then you may find that you end up with somebody who, after a period of time, turns out to be extremely homophobic when you might be lesbian or gay.

Such a situation can create very serious problems for disabled lesbians and disabled gay men. There have been circumstances where people have been literally deserted by their P.A because they have found out that the disabled person was lesbian or gay.

There are examples where P.A's have come into people's bedrooms in the morning to get someone out of bed and found them sleeping with somebody of the same sex. After realising that it wasn't just a friend but a partner the P.A has got very upset and walked out leaving the disabled person without assistance or support. Another situation which causes difficulties is when P.A's leave because they find magazines or literature of a lesbian and gay nature around the house. There are instances where P.A's have actually gone and told neighbours. This can create very serious problems, especially if the P.A user needs to enlist the help of a neighbour on an occasional basis. Disabled lesbians and disabled gay men in this type of situation are sometimes in physical danger; they run the risk of verbal and physical abuse and also having bricks thrown through their window.

It is important that people think seriously about equal opportunities for many other reasons too. For instance, there is the important issue of parenthood. If their sexuality is discovered and made public then disabled lesbians and disabled gay men run the risk of losing custody of their children -if they have any. As you can see disabled lesbians and disabled gay men are extremely vulnerable in many ways.

Consequently, when employing P.A's, disabled lesbians and disabled gay men have to decide at what point during the interview they can disclose their sexuality -when to come out and say 'I am lesbian' or 'I am gay'? The PA user who is gay also has to prepare themselves for any signs of outrage from the applicant. If they choose not to bring the subject up at the interview, do they leave it for a while and raise it later in casual conversation? This is something that can be very difficult to deal with. How to deal with it correctly is something

I cannot answer. It is something that people can only deal with as they come to terms with their sexuality themselves and through experience.

I hope people understand the importance of raising issues relevant to disabled lesbians and disabled gay men at a seminar like this. It has taken a long while and a lot of effort to get to this position. I hope that this will be the beginning of a useful discussion within the disability movement.

These are also important considerations for disabled people who are bisexual. They too have to decide how their sexuality fits in with their programme of employing P.A's. There are a lot of issues here which I do not really have time to talk about but which have to be considered.

It is crucial that as we develop models of independent living we take account of the sexual and cultural diversity within the disabled community. It is important that in our discussions of oppression, we include in those discussions the experiences of those people who experience more than one form of discrimination.

For too long disabled lesbians and disabled gay men have had to deal with homophobia -having to read about it in the lesbian and gay press and possibly having bricks thrown through their window -without any real support from the disabled community. Such issues need to be included in all discussions about disabled people, independent living and personal assistance.

All those people who work in the disability field, particularly those who are training, also need to be aware of the issues raised by sexuality. It is important not to skate over them, to ignore them, or to pretend that diverse sexuality does not exist within the disabled community. If disabled people are to be treated on a truly equal basis with non-disabled people then we have to create space for discussions about sexuality -whatever that may ultimately mean.

To this end an organisation for disabled lesbians and disabled gay men has been set up by disabled lesbians and gay men known as REGARD (see Resources for REGARD's address). It provides an excellent forum for disabled lesbians and disabled gay men to come together and talk about issues relating to sexuality. We have found that by sharing our experiences we can help each other deal with important issues relating to our sexual identities, independent living, and personal assistance use.

Sexuality is not simply an issue for only disabled lesbians and disabled gay men, it is an issue for the whole disability movement. There is a lot that can be gained from different minorities within the disabled community coming together to deal with the discrimination that we all face. We need to look at ways in which we can unite to fight and overcome that discrimination. It should not be 'us' (disabled lesbians and disabled gay men) and 'them' (disabled women, disabled black people and disabled heterosexuals) it should be us all - the disability rights movement. Together we shall succeed.

7. The Role of Centres of Independent/Integrated Living

John Evans

This is the last session of the last day and I know you've had a lot of information to deal with over the weekend, and Centres of Independent/Integrated Living (CIL's) have been mentioned a lot, but I have been asked to talk a little bit about CIL 's and how they actually started - initially in the United States and later in this country. We now have a ten year history of CIL's in Britain, I want to look at what's been going on and tell you something about some of the issues raised during that time.

As far as CIL's are concerned, it all started in Berkeley, California in 1973. The climate at that time was quite ripe for this type of organisation. It was just after the growth of the Peace Movement, the Women's Movement and the Lesbian and Gay Movements. All sorts of things were going on in America at that time - particularly in California.

It started in the University at Berkeley. There were three severely impaired students who were able to study because the university provided them with personal assistants (P.A's). It was something that was totally unique at that time -it had never happened before.

These students all graduated and when they finished they felt that the P.A service had been so successful that they decided to take it out into the community. They wanted to take the idea of personal assistance out of the campus and into the community. Working with the authorities in Berkeley they did just that. They had decided that they wanted to live out in the community like everybody else and they did it.

They worked together with the Berkeley authorities and set up what became the first CIL. They were referred to as the 'quad squad' -mainly because most of them were paralysed from the shoulders down. One of them in fact uses an iron lung and he ended up being what is the equivalent of the Director of Social Services in California.

The idea of personal assistance in the development of independent living is crucial. I think it is fundamental to independent living. Without that support, without that mechanism severely impaired people couldn't possibly function independently.

When they set up the Berkeley CIL it was all about control. It was about disabled people taking control of the services that they wanted. They set up five basic core services. This led to an important development in this country. The five were: 'housing', which is sensible, when you start out you need somewhere to live. The second was 'personal assistance'. If disabled people were going to live independently in houses then they needed that kind of support. The third was 'accessible transport', because they didn't want to just live in their own homes. They wanted to be able to move about in the community. Without accessible transport they weren't going to be able to do that. The fourth service was 'access'. They knew that there was no point in being able to move about in the community unless they had places to go, places to study and jobs to go to. So they wanted an accessible environment. Fifth, and finally, and very important at that time, they wanted 'peer counselling' to support disabled people. This was counselling and support at all levels, be it emotional, support, be it advice, information or whatever.

I'd like to say something about counselling because it's now something of a loaded word and it's often referred to in critical terms. We disabled people, view it as an area of professional domination. These days we'd be better using the phrase 'peer support' or 'peer models' as opposed to 'peer counselling'.

The CIL that started in Berkeley flourished and within ten years there were 200 of them all over the United States. It was a major development which showed that these centres were badly needed.

What then is a CIL ? When the centre in Berkeley was set up it had two basic premises. The first was that it was an organisation that was run and controlled by disabled people -this was paramount, control was crucial; secondly, it should serve people with all sorts of impairments and from all backgrounds - whatever minority background that might be.

As CIL' s developed they responded to the needs of the local community. Wherever you see CIL' s you find that they are often quite different. Some focus on personal assistance, others focus on transport - some are quite political. The reason for this difference is that they have responded to the needs of local disabled people.

In this country in the early 1980's two centres started out at roughly the same time; the Hampshire CIL (HCIL) and the one in Derbyshire (DCIL). To give you an idea of what they are about I'd like to read out the definition that Derbyshire came up with. A CIL is:

'local services to meet local needs wherever possible under local control. A CIL is a central support resource underpinning local initiatives by disabled people. A CIL is a resource to assist the redirection of help and social services toward independent living. A CIL is a symbolic consciousness raising beacon to assist the process of shifting attitudes and low expectations .A CIL is a joint collaborative practical service as distinct from the watch-dog pressure group role of the Coalition itself.'

The last point is important because there is often a misunderstanding as to whether a CIL is a service providing agency or whether it is actually a political pressure group. I think Derbyshire clarified that by forming the Derbyshire Coalition of Disabled People (DCDP) first.

That was the difference between the first two CIL' s in this country. Derbyshire began with a coalition of disabled people whereas Hampshire started with people actually moving out of an institution. I think what happened in Hampshire was similar to what happened in Berkeley, California in that, instead of moving out of a university into the community, disabled people in Hampshire moved out of an institution.

There was a group of disabled people in Hampshire living in a Cheshire Home who decided that they would negotiate with the authorities sponsoring them to live there. They wanted some of that money to enable them to live in the community -it took some time to convince the authorities that the idea would work.

They did convince the authorities, the idea did work, and those people moved out into the community one by one. As they moved out they decided that they didn't just want the CIL for themselves, they wanted to get together with other disabled people already living in the community struggling to survive and avoid going into institutions.

So when HCIL started it had a real focus on personal assistance and it developed in this direction over the years. The HCIL as an organisation has become quite well known in the area of personal assistance because of its publications. That has been one of our main focuses.

In Derbyshire it's been quite different. They have looked at the whole thing and to go back to those basic five core services started in Berkeley, Derbyshire have added an extra two. They added 'information', paramount in enabling disabled people to acquire what they need, and 'technical assistance'. This is technical assistance that would enable disabled people live that much more independently.

As other organisations have been set up, a further four basic needs have been added to the list. These are 'income', money is crucial, 'employment', a job, 'education' and 'advocacy and training'. 'Centres of independent/integrated living and the independent living movement are all about advocacy and empowering disabled people to speak up, to become active, and to empower their organisations. ' Advocacy and training' is a very important part of that process.

We know that advocacy and training goes on at many different levels but an aspect of training that we do in Hampshire is training specifically for independent living. We try to develop independent living skills. We try to give disabled people the skills and resources to survive in the community.

When people have lived in institutions they have been conditioned and segregated from society. They need to build up and acquire new skills to achieve independence. Even simple things like managing one's own budget have to be learned. People need to know how to manage their own p .A's.

I think in this country there are now eight CIL' s altogether. As well as Derbyshire and Hampshire there's one in Southampton. In London there's Islington, Lambeth and Greenwich, there's Lothian in Scotland and there's one in Avon. So they are developing, and when we see them developing we see strong groups of disabled people in those areas. They are operating and creating new services that are needed.

As they develop the whole idea of networking becomes important. When people get together where independent living is concerned, people need networks to exchange ideas and information. Hampshire have got the 'Personal Assistance Newsletter' which I think has got over two hundred subscribers. These are all people with severe impairments who are personal assistance users.

Hampshire publishes the Newsletter on behalf of the BCOOP's (British Council of Organisations of Disabled People's) Independent Living Committee. It covers the whole country. That's where we gain our expertise.

At this seminar there are lots of different disabled people with different strengths and talents, and we can share those talents. By sharing them we can develop the independent living movement in this country.

To sum up I would like to read out something I wrote a couple of months back, Independent living is a lot of things but for me it is about:

'disabled people taking control of their lives and changing their lives. It is often thought to be about enabling people to live in their own homes with support. But this is just part of the picture. Life is more than just a house and getting up and going to bed. Independent living is about the whole of life and it encompasses everything. We want equal opportunities. We want equal citizenship. These are the issues that drive the independent living movement. It is philosophical, it is political, it is about integration and disabled people becoming apart of this world and not separate, segregated and second class. That is what we are actually after and that is why independent living is so important. Independent living is about disabled people confronting the daily discrimination we experience. It is about creating choices. We are individuals. Independent living gives expression to the uniqueness we have as individuals. It is not an automatic mechanised service coming to our door. It is recreating our own service day in and day out in the way that we want and in the way that we know best. Everyday is different even if you have what is supposedly a routine lifestyle. That is the fascination of independent living. Disabled people are no different to anybody else. We develop as people socially, economically, politically and philosophically. Independent living is a dynamic process. It is about identifying choices and creating solutions .It is a way of life that grows as you grow and develops as you develop. We want to see disabled people acting economically, we want to see them moving into their own homes and getting jobs. We want to have equal rights. Independent living is not just hands on time and bricks and mortar. It is about people's lives and the quality of their lives, and who we are as people. That is the important thing '.

It's important not to lose sight of that when we are thinking about the practicalities of independent living.

8. Workshops

The following is a summary of topics discussed in the workshops which followed each key speaker. The summaries were taken from items listed on flip charts in workshop areas and notes taken by participants .

- a. An Introduction to Independent/Integrated Living and Personal Assistance
 - i. 'Newcomers' to the idea of independent living were surprised that the movement had been in existence for so long.
 - ii. Several had little understanding of the distinction between the 'medical' and the 'social' models of disability but were keen to learn more.
 - iii. Most 'newcomers' were unaware of the difference between organisations controlled and run by disabled people and traditional organisations controlled and run by non-disabled people.
 - iv. There was a general feeling that disabled people should have a greater say in all organisations concerned with disability.
- b. Managing a Personal Assistant
 - i. People reliant on local authority and voluntary services felt that they were unable to plan their lives as they wanted to.
 - ii. They felt as if they were 'dictated' to by the service provider
 - iii. It was generally agreed that with few exceptions service providers made users feel overdemanding when they asked for more flexible services.
 - iv. The attitudes of some providers, such as home helps, made people feel as if they were 'doing you a favour' and that there were always other 'disabled persons' in greater need.
 - v. It was stressed that there should be more opportunity for disabled people to co-ordinate their own personal assistance services.

- vi. Some potential users were unsure of actually 'employing' a personal assistant but wanted to know more about co-operatives and 'third party schemes'.

- c. The User/Personal Assistant Relationship

- i. Experienced users identified a number of problems. These included communication difficulties resulting from the conflicting expectations of both the user and the personal assistant (P.A).
- ii. Overfriendliness on the part of the P.A was seen as a common problem for many.
- iii. It was generally felt that the complexity of the user/P.A relationship meant that it is very susceptible to abuse -by both parties.
- iv. The lack of privacy was seen as a problem for some P.A users.
- v. Others suggested that there was a danger of user over dependence especially if the user/P.A relationship was a particularly long one.
- vi. The issue of the 'unionisation' of P.A's was mentioned as a possible threat to user control.
- vii. Participants agreed that these problems could only be overcome by a 'professional' approach, ie. well planned interviews and established employment procedures -regular employment reviews, standardised disciplinary procedures etc.
- viii. All present stressed that there was an urgent need for more information on these subjects and that organisations like the BCODP should seek the appropriate resources to organise more conferences and meetings for disabled people to share and learn from their individual and collective experiences.

- d. The Role of Centres for Independent/Living

- i. Discussions focused around the need for more Centres for Independent/Integrated Living (CIL's) -in particular how to establish new ones.

- ii. Participants cited appropriate information as a necessary prerequisite for setting up a CIL -established organisations were identified as the best source for such data.
- iii. Local Authorities, District Health Authorities and Training and Enterprise Councils (TEC's) were mentioned as possible sources of support.
- iv. In terms of likely locations it was noted that some organisations were initially home based; DIAL (Disability Information and Advice Line) was given as one example.
- v. Participants noted the dangers of professional involvement -particularly in terms of the monopolisation of information and resources.
- vi. It was also pointed out that strong local groups with their own organisations and CIL's can safeguard against 'tokenism' in local services. Derbyshire Coalition of Disabled People's (DCDP's) involvement with the local authority was cited as a good example.
- vii. All present emphasised the importance of ensuring that all new CIL' s and associate organisations should remain fully accountable to local disabled people and their needs -whatever those needs may be, and that there should be strenuous efforts to establish stronger networks of disabled people.

e. Fringe Workshops

- i. Stewart Bracking held a workshop on the attempted genocide of disabled people in Nazi Germany during the 1930's and 40's.

The subsequent discussion focused on the links between these events and the growing emphasis on euthanasia and the resurgence of fascism in many western societies.

All present expressed deep concern over these developments because of their implications for disabled people.

- ii. Katherine Smith of 'Active Assistants' held a workshop for personal assistants (P.A's). But no feedback was forthcoming from this event.

iii. An impromptu workshop was held by Carl Ford for established P.A users. The discussion revolved around the urgent need for more and stronger networks of P.A users to enable people to share and explore their experiences -both good and bad. It was agreed that this was essential if self operated personal assistance schemes for disabled people were to develop further.

f. General Discussions

i. A major point to come out of general discussions at the Seminar was a desire to set up a national organisation specifically for 'young' disabled people. Participants felt that this was essential for two main reasons.

Firstly, because for many people with impairments the full extent of society's oppression of disabled people only becomes apparent during the adolescent or young adulthood period. The experience of 'disability' - unemployment, an inaccessible environment, social isolation etc. -is often far more acute for people leaving school or college and trying to establish an adult identity.

Secondly, if the disability rights movement is to grow and develop, then it is important that established disabled people's organisations recruit more young disabled people with new ideas and commitment.

9. 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, SE109EQ. Telephone: 081 3052221.

'Sourcebook Towards Independent Living'. HCIL Books, c/o. Mark Walsh, 3 Churchfield Headley, Bordon, Hampshire GU35 8TF .

'The Personal Assistance Users Newsletter'. BCODP, De Bradelei House, Chapel Street, Belper, Derbyshire, DE56 1AR, Telephone: 0773 828182

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 PL700 entitled 'Written Statement of Main Terms and Conditions of Employment'.

The ACAS advisory handbook 'Discipline at Work' can be obtained from ACAS Reader, PO Box 797, London. SE8 4JX. Telephone Enquiries: 071 3965100.

Other Useful Publications

'Disabling Imagery and the Media' Barnes, C. (1992) BCODP, De Bradelei House, Chapel Street, Belper, Derbyshire, DE56 1AR. Telephone: 077: 828182.

'Cash for Care: A Question of Choice?' Craig C. (1992) Social Policy Research Unit, The University of York, York, YO1 5DD. Telephone: 0904433608.

'Disability Rights Handbook' (1993/4) Disability Alliance, Universal House, 88 - 94 Wentworth Street, London, E1 7SA. Telephone: 071 247 8776.

'Cash for Care: The Experience of Independent Living Fund Clients' Kestenbaum, A. (1992) Independent Living Fund, PO Box 183, Nottingham, NG8 3RB. Telephone: 0602 290423/0602 290427.

'Greenwich Personal Assistance Schemes: An Evaluation (1992) Oliver, M. and Zarb, G. Greenwich Association of Disabled Peoples' CIL, Christchurch Forum, London, SE109EQ. Telephone: 081 3052221.

'Building Our Lives' Laurie, L. (1991) Shelter, National Campaign for the Homeless, 88 Old Street, London, EC1 V 9HU. Telephone: 071 253 0202.

'Our Homes Our Rights', Morris, I. (1990) Shelter, National Campaign for the Homeless, 88 Old Street, London, EC1V 9HU. Telephone: 071 2530202.

Organisations

Avon Centre for Independent Living, (ACIL) Easton Community Centre, Kilburn Street, Easton, Bristol, BS5 6A W . Telephone: 0272 412063.

British Council of Organisations of Disabled People, De Bradelei House, Chapel Street, Belper, Derbyshire, DE56 1AR. Telephone: 0773 828182.

Derbyshire Centre for Integrated Living, (DCIL) Long Close, Cemetery Lane, Ripley, Derbyshire, DES 3HY. Telephone: 0773 740246.

Disability Alliance, Universal House, 88 - 94 Wentworth Street, London, E1 7SA. Telephone: 071 247 8776.

Disablement Income Group, (DIG) Unit 5, Archway Business Centre, 19-23 Wedmore Street, London, N19 4RZ. Telephone: 071 263 3981.

Disabled Living Foundation, 380 -384 Harrow Road, London, W9 2HU. Telephone: 071 2896111.

Disability Resource Team, (DRT) 3rd Floor, Bedford House, 125 -133 Camden High Street, London, NW1 7JR. Telephone: 071 4824896.

Greater London Association of Disabled People, (GLAD) 336 Brixton Road London, SW9 7 AA. Telephone: 071 274 0107.

Greater Manchester Coalition of Disabled People, (GMCDP) Unit 33, Cariocca Business Park, 2 Hellidon Close, Ardwick, Manchester, M12 4AH. Telephone: 061 2735154/5.

Greenwich Association of Disabled People, (GAD), Greenwich Centre for Independent Living, Christchurch Forum, Trafalgar Road, Greenwich, London, SE109EQ. Telephone: 081 305221.

Hampshire Centre for Independent Living, (HCIL) 4 Plantation Way, Whitehall, Bordon, Hampshire, GU35 9HD. Telephone: 0420 474261.

Independent Living Alternatives, Fulton House, Fulton Road, Wembley Park, Middlesex, HA9 OTF. Telephone: 081 9028998 ext: 228.

Islington Disablement Association, (IDA) 90 -92 Upper Street, London, N1 ONP. Telephone: 071 226 0137.

Lambeth Centre for Integrated Living, (LCIL) Barstow Crescent, Palace Road, London, SW23NS. Telephone: 081 671 8892.

Lothian Centre For Integrated Living, (LCIL) 13 Johnston Terrace, Edinburgh, EH1 2PW. Telephone: 031 2253555.

REGARD, BM REGARD, London, WC1N 3XX.

Shropshire Disability Consortium, The Shropshire Disability Resource Centre, Lancaster Road, Harlescott, Shrewsbury, Shropshire, SY1 3NJ. Telephone: 0743 344599 Ext: 236.

Southampton Centre For Independent Living, (SCIL) 6 Northlands Road, Southampton, SO1 2LF. Telephone: 0703 330982.

Spinal Injuries Association, (SIA) 76 St James' Lane, Muswell Hill, London, N103DF. Telephone: 081 444 2121.

Statutory Authorities

Area Health Authority or District Health Authority - they should provide information on health related services like chiropody, physiotherapy, health visitors, district nurses and so on.

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.

District Council Housing Departments - contact for housing problems and information about grants such as the Disabled Facilities Grant for adapting inaccessible homes.

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).

Personal assistance -for existing claimants contact the

'Independent Living (Extension) Fund' PO Box 183, Nottingham, NG8 3RB.
Telephone: 0602 290423/0602 290427,

and for new applications get in touch with the 'Independent Living (1993) Fund'
PO Box 183, Nottingham, NG8 3RB. Telephone: 0602 290423/0602 290427.

Personal Assistance

Active Assistance, 2nd Floor Office, Stricklandgate, Kendal, Cumbria, LA9 4RA. Telephone: 0539 730674.

Community Service Volunteers, (CSV Independent Living Scheme) 237 Pentonville Road, London, N1 9NJ. Telephone 071 2786601.

Independent Living (Extension) Fund, (see above).

Independent Living (1993) Fund, (see above).

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.

10. Seminar Participants

Lata Allman	Barbara Lisiki
Jany Ayscough	Sue Maynard
Karen Ball	Florence E Mitchell
Colin Barnes	Gwen Morrison
Nasa Begum	Joan Oaks
Stewart Bracking	Kim Pang
Liz Carr	Anne Rae
Chris Chappell	Richard Shaw
Sue Croshaw	Jo Smith
Julia A Davison	Ian Stanton
Joan Dawe	Mike Squire
Doreen Edwards	David Tares
John Evans	Brian Tolson
Carl Ford	Rachel H Walker
June W Fletcher	Michael Waterhouse
Wendy Glover	Vera Wilmour
Jonathan Griffith	Myra Wyers
Bridget Hardy	
Stephen Haslem	
Alan Holdsworth	
Mark Holt	
Winifred Jackson	
Cara Gay Jones	
Steve Jones	
Stephen Joyce	
Jacqueline Kelly	
Dennis Killin	
Elizabeth Laybourne	
Paul Lindoe	

Five participants were unable to attend the seminar due to last minute changes in their personal circumstances, and one person preferred not to have their name included on this list.

Appendix 1

Human Rights and Disabled People Why Anti-Discrimination
Legislation is Essential

British Council of Organisations of Disabled People

Throughout the 1980's disabled people watched with a growing sense of disbelief as the traditional voluntary organisations continually failed to present disability issues as the infringement of their basic human rights, and successive governments failed to introduce anti-discrimination legislation to enable them to participate fully in the economic and social life of the community.

However, the British Council of Organisations of Disabled People (BCODP) since its formation in 1981 has insisted that disabled people are denied their basic human rights in British society. This is because disabled people encounter discrimination daily and do not have the same rights as non-disabled people.

Parents of disabled people children do not have the right to send their child to local schools. Employers can discriminate openly against disabled workers, many disabled people don't have the right to choose what time they will get up in the morning or go to bed at night. Disabled people don't even have the same legal protection as women and black people.

While the Government and many of the traditional voluntary organisations have now come to acknowledge the existence of discrimination against disabled people, it is again BCODP which has identified just how pervasive and pernicious such discrimination actually is. The type of discrimination encountered by disabled people is not just a question of individual prejudice, it is institutionalised in the very fabric of our society and is faced by disabled people every day of their lives.

Institutional discrimination operates throughout society and is supported by history and culture. Historically, disabled people have been viewed with a variety of emotions including suspicion, ridicule and pity. Until fairly recently they have been excluded almost completely from all aspects of community life. Our culture is full of disablist language and imagery which keeps the traditional fears and prejudices alive.

Institutional discrimination is evident when the policies and activities of all kinds of organisations result in disabled people being denied the same treatment or equal access to goods and services as non-disabled people. Modern welfare services continually deny disabled people their basic rights by refusing disabled people their entitlements, by constantly redefining or refusing to acknowledge their needs, or by providing services which infringe on their freedom and/or invade their privacy.

BCODP believes that the only way institutional discrimination can be tackled is with anti-discrimination legislation, as a number of other countries as politically diverse as Sweden and the USA have realised.

To this end, BCODP will campaign continuously until anti-discrimination legislation reaches the statute books. Already it has carried out a two year research project financed by the Joseph Rowntree Foundation and has produced a book on the subject entitled 'Disabled People in Britain and Discrimination' by Colin Barnes. At its recent tenth anniversary Annual General Meeting it launched its political campaign for anti-discrimination legislation, which will continue until the shameful walls of exclusion really do come tumbling down.

For further information contact:

BCODP

De Hradelei House Chapel Street
Belper
Derbyshire
DE56 1AR

Telephone: (0073) 828182

Minicom: (0773) 828195

Fax: (0773) 829672

Director: Richard Wood

Appendix 2

European Conference on Personal Assistance Services for Disabled People Demands Independent Living for all Disabled People

European Conference on Personal Assistance Services for Disabled People organised by the international disability movement with the help of GRAEL in the Rainbow Group in the European Parliament and the GRUNEN in the German Bundestag.

We, more than a hundred disabled people from Netherlands, United Kingdom, Denmark, Italy, Switzerland, Sweden, France, Austria, Finland, Belgium, USA, Hungary, FRO, and Norway have come together from April 12 to 14th at Strasbourg in France to raise the issue of personal assistance services as a prerequisite for independent living for disabled people.

In our view, independence is not measured by the quantities of tasks one can perform without assistance, but the quality of life one can have with assistance. Assistance in the context of independent living is given within the framework of a civil right and a service under the control of the recipient -where, when how and by whom. Today these services are not being realised in any quantity in the European community.

Our coming together here in Strasbourg is the result of growing disability movements in countries all over the world. Increasingly we, disabled people, are raising our voices to speak against the warehousing of disabled people in special institutions, and against the denial of basic equal rights for disabled people by medical experts, policy makers and administrative officials.

In sharing our experience about the social welfare systems and laws in our respective countries, we have found that by the exclusion of disabled people from the mainstream of society and the denial of access to personal assistance services, we are prevented from entering the workforces and other spheres of social life. We are denied the right to independent living. These denials are also the basic sources of discrimination against disabled people.

We demand social welfare systems that include personal assistance services that are consumer controlled and which allow for various models of independent living for disabled people, regardless of impairment and income. We demand social welfare legislation which recognises these services as basic civil rights

and which provide necessary appeal procedures. This conference is proof of a growing disability movement that will not stop until independent living and full participation in society are realised for all disabled people.

Resolutions

1. Personal assistance services are a human and civil right which must be provided at no cost to the user. These services shall serve people with all types of impairments and all ages on the basis of functional need, irrespective of personal wealth, income, marital and family status.
2. Personal assistance users shall be able to choose from a variety of personal assistance service models which together offer the choice of various degrees of user control.
3. Services shall enable the user to participate in every aspect of life such as home, work, school, leisure, travel and political life etc. These services shall enable disabled people, if they so choose, to build up a personal and family life and fulfil all the responsibilities connected with this.
4. These services must be available long term for anything up to 24 hours a day, seven days a week, and similarly on a short term or emergency basis. These services shall include assistance with personal bodily functions, communication, household, mobility, work and other related needs. In the assessment of need the consumer's view must be paramount.
5. The funding authority shall ensure that sufficient funds are available to the user for adequate support, counselling, training of the user and the assistant, if deemed necessary to the user.
6. Funding must include assistant's competitive wages and employment benefits, all legal and union required benefits, or services.
7. Funding shall be a legislative right and payment must be guaranteed regardless of funding source or local government arrangements. Funding shall not be treated as disposable/taxable income and shall not make the user ineligible for other statutory benefits or services.
8. The user should be free to appoint whoever they choose as personal assistants, including family members.

9. No individual shall be placed in an institutional setting because of lack of resources, high costs, sub-standard or non-existent services.
10. There shall be a uniform judicial appeals procedure which is independent of funders, providers and assessors; is effected within a reasonable amount of time and enables the claimant to receive legal aid at the expense of the statutory authority.
11. In furtherance of all the above, disabled people and organisations controlled by them must be decisively involved in implementation and development.

European Conference on Personal Assistance Services
for Disabled People
12 - 14 April 1989
Strasbourg,
France

Appendix 3

The British Council of Organisations of Disabled People

Seminar on Independent Living and Personal Assistance, 7, 8, 9, August 1992
Herewood College, Coventry

Seminar Application Form

This is the first seminar on independent living and personal assistance use in Britain. On behalf of the BCODP the seminar organisers will strive to enable anyone who uses or wishes to use personal assistants to attend. (A personal assistant is someone who is directed by a disabled person to provide the appropriate personal and practical assistance to enable the disabled person to live independently in the mainstream of society).

As you will appreciate, for us to meet adequately the variety of personal assistance and accommodation needs of all potential participants, it is essential that we have access to specific information about those needs. We hope that this application form will provide that information. Consequently applicants are asked to complete in full. However, given that some of the information requested is of a highly sensitive nature, it is important to note that all received data will be treated in the strictest confidence.

If you have queries about the event, transport or completing this form members of the Independent Living Seminar support group will be happy to discuss them with you. Telephone 0523 334414 or 0532 301097

Application Form

Name

Address:

.....

.....

Telephone number (day)
..... (evening)

1. Do you require seminar information in:

a LARGE PRINT?

Please tick as appropriate YES NO

b tape?

Please tick as appropriate YES NO

c braille?

Please tick as appropriate YES NO

d another language such as Urdu or Hindi for example?

Please tick as appropriate YES NO

if so please specify

2. Will you need a British Sign Language interpreter?

Please tick as appropriate YES NO

(Note: An induction loop is provided in all conference rooms).

3. Would you prefer a single or a twin bedded room?

Please tick as appropriate single

twin

(Note: Twin bedded rooms are for people wishing to share with a personal assistant. All rooms have a 24 hour call bell system).

4. Will you need creche facilities?

Please tick as appropriate YES NO

5. Have you any special dietary requirements?

Please tick as appropriate YES NO

if so what are they?

.....

.....

6. Will you need car parking facilities?

Please tick as appropriate YES NO

7. Do you manage or employ your own personal assistance?

Please tick as appropriate YES NO

8. Are you currently using personal assistance services provided by family, statutory organisations or others?

if so please give details they?

.....

.....

9. How many persons assist you at any one time during the course of the day?

Please specify

.....

.....

10. Will you be bringing a personal assistant with you?

Please tick as appropriate YES NO

(Note: meals and accommodation for personal assistants will be provided free of charge during the seminar).

11. Would you like the BCODP to provide personal assistance for you?

Please tick as appropriate YES NO

12. Would you prefer a male or a female personal assistant?

Please tick as appropriate

13. Will you require a full 24 hour service (active awake assistance throughout the night)?

Please tick as appropriate YES NO

If not:

14. Will you require turning during the night at specified times?

Please tick as appropriate YES NO

15. Will you require assistance with bodily functions?

Please tick as appropriate YES NO

Please give details
.....
.....

16. Will you require assistance getting up in the morning and going to bed at night?

Please tick as appropriate YES NO

17. Will you require assistance at mealtimes?

Please tick as appropriate YES NO

18. Will you require more than one person to assist you for some activities during the course of the day?

Please tick as appropriate YES NO

If so how many?
and how often?

19. Will you require the use of particular equipment such as a hoist or a commode for example?

Please tick as appropriate YES NO

If so please give details
.....
.....

20. Finally, if you have any specific needs which a personal assistant for the seminar should know about, and which do not appear to be covered above please use the following space to let us know what they are.

.....

.....

.....

.....

.....

21. Please return this form to:

Colin Barnes
The Seminar Co-ordinator
The British Council of Organisations
of Disabled People
Department of Social Policy, and
Sociology
The University of Leeds
Leeds
LS2 9JT

(Note: There are only a limited number of places available at this event and early indications suggest that competition for inclusion is likely to be high. To avoid disappointment please return this form as quickly as possible).

Appendix 4

British Council of Organisations of Disabled People

Seminar on Independent Living and Personal
Assistance, 7, 8, 9, August 1992
Herewood College, Coventry

Timetable and Agenda

To ensure that the timetable is not too overwhelming, the organisers hope to limit talks to fifteen minutes, and workshops to three quarters of an hour. We recognise that such constraints may not give participants sufficient time to explore fully the issues raised in each session, but we believe there will be adequate opportunities for informal discussion elsewhere in the programme.

Friday 7th August

1.30 - 4.00 pm	Arrival, afternoon tea and settling in.
4.00 - 5.00 pm	Introduction: An opportunity for participants to meet the organisers, meet each other, and get to know more about the Seminar's Aims. Speakers: Lata Allman, Leicestershire Coalition of Disabled People. Colin Barnes, BCODP researcher and Seminar Co-ordinator. Carl Ford, BCODP Independent Living Committee. Richard Shaw, BCODP Independent Living Committee.
5.00 - 5.30pm	Videos and free time.
5.30 pm	Dinner.
7.00 pm - onwards	Free time for social activity. A licensed bar will be available.

Saturday 8th August

- 8.30 am Breakfast
- 10.00 - 11.00 am An Introduction to the idea of Independent/Integrated Living and Personal Assistance.
Speaker: Stuart Bracking, Muscle Power.
- 11.00 - 11.30 am Morning Coffee.
- 11.30 - 12.30 pm Managing a Personal Assistant.
Speakers: Carl Ford, BCODP Independent Living Committee and PA user.
Richard Shaw, BCODP Independent Living Committee and PA users.
- 12.30 - 2.00 pm Lunch
- 2.00 - 3.00 pm The User/Personal Assistant relationship.
Speakers: Carl Ford, BCODP Independent Living Committee and PA user.
Richard Shaw, BCODP Independent Living Committee and PA user.
- 3.00 - 4.30 pm Afternoon tea.
- 3.30 - 4.30 pm Financing Personal Assistance and the Independent Living Fund: a choice to make.
Speaker: Deborah Kent, Independent Living Fund.
- 4.30 - 5.30 pm Free time, videos and fringe workshops.
The genocide of disabled people in Nazi Germany and its implications.
Speaker: Stuart Bracking, Muscle Power.
Providing personal assistance, an agency perspective.
Speaker: Kathryn Smith, Active Assistance.

- | | |
|-------------------|--|
| 5.30 pm | Dinner. |
| 8.00 pm - onwards | Free time for social activity. A licensed bar will be available. |
| | Cabaret. |

Sunday 9th August

- | | |
|------------------|---|
| 8.30 am | Breakfast. |
| 10.30 - 11.30 am | Centres of Independent/Integrated Living (CIL's) and the role of Networks of Personal Assistant Users.
Speaker: John Evans, BCODP Independent Living Committee, PA user, and Deputy Chair of BCODP. |
| 11.30 - 12.00 pm | Morning coffee. |
| 12.00 - 12.45 pm | Plenary session.
Chair: Jane Campbell, Co-chair of BCODP. |
| 12.45 pm | Lunch. |

Appendix 5.

The British Council of Organisations
of Disabled People

Seminar on Independent Living and Personal Assistance

7, 8, 9, August 1992

Herewood College Coventry

Seminar Evaluation Form

If you have any comments, good or bad, on the BCODP's recent seminar on independent living and personal assistance please let us know. Your views are essential if we are to make improvements to future events.

Use the following space to comment on:

1. Travel arrangements

.....
.....
.....

2. Accommodation

.....
.....
.....

3. Personal assistance services provided by the BCODP

.....
.....

4. Speakers

.....
.....
.....

5. Workshops

.....
.....
.....

6. Cabaret

.....
.....
.....

7. General organisation

.....
.....
.....

8. Finally, please use the following space, if you have anything else to say about the Seminar

.....
.....
.....

.....

.....

.....

.....

Please return this form to:

Colin Barnes
The Seminar Co-ordinator
The British Council of Organisations
of Disabled People
Department of Social Policy and
Sociology
The University of Leeds
Leeds
LS2 9JT