

Personal Assistance Schemes

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GREENWICH

**Personal
Assistance
Schemes**

An Evaluation

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FOREWORD

In my role as Minister for Disabled People, I have had the privilege of talking with many individuals who provide services for disabled people and an even greater number of people who themselves have disabilities of one kind or another. Invariably, disabled people I speak to express a strong desire to lead an independent life, integrated to the greatest possible extent with the able bodied community and most fundamentally, to be able to make their own decision. In order to make these decisions, and to exercise real choice, disabled people need accurate and relevant information. Having made their decisions and chosen freely from the alternatives, they should then receive the wider support and understanding of society to participate fully in the life of the community.

This report on Personal Assistance Schemes in Greenwich shows that as well as being cost effective, such schemes offer disabled people a greater degree of independence when compared with traditional forms of provision.

I commend this report to service providers and all those who are concerned about making the lives of disabled people more independent.

NICHOLAS SCOTT

Minister for Social Security and Disabled People

ABOUT THE EVALUATION

Mike Oliver and Gerry Zarb have been commissioned to carry out an evaluation of the Greenwich Personal Assistance Schemes (PAS) project. Initial discussions were held with the evaluators in February 1990 and preliminary plans for the evaluation outlined. The full evaluation commenced in July 1990 (when funding for this work was confirmed), and was completed in September 1992.

Three primary objectives were identified for the evaluation:-

- i) evaluation of the viability of Personal Assistance Schemes;
- ii) evaluation of the cost effectiveness of Personal Assistance Schemes;
- iii) evaluation of the role of the Personal Assistance Advisor based at Greenwich Association of Disabled People (GAD);

The preferred method for carrying out the evaluation was initially defined in a statement by GAD in November 1989:-

"We believe that evaluation of the scheme is vital and recognise that such evaluation should be independent of the project. Evaluation should be continuous throughout the duration of the project ... If disabled people throughout the U.K. are to benefit from this project, and service providers are to be persuaded of the viability of self-operated schemes it will be important to document the stages in the scheme, successes and failures, and produce a detailed report."

While the evaluators are completely independent, it was considered inappropriate for the evaluation to be carried out without close and continuous consultation with GAD and local Personal Assistant Scheme users. Consequently, rather than simply produce periodic reports, the evaluators have held regular meetings with GAD with a view to feeding issues arising from the evaluation into their own work, to monitor progress of the evaluation itself, and to review priorities. Apart from this ongoing consultation, the evaluation has also included a group interview with local Personal Assistance Scheme users, a follow-up survey on peoples experiences of running their own Personal Assistance Schemes, monitoring and evaluation of the work of the Personal Assistance Advisor, and an analysis of the cost effectiveness of Personal Assistance Schemes compared to other options for meeting disabled people's support needs.

In addition to this report and an interim report produced at the end of the first year, a series of working papers on different aspects of the evaluation have been produced. These are listed below, and copies will be available direct from Greenwich Association of Disabled People on request:-

- Evaluation of Greenwich Self Operated Care Schemes: First Year Report (March, 1991)
- Evaluation of Greenwich Self Operated Care Schemes: Summary of First Year Report (March, 1991)
- Greenwich Personal Assistance Schemes: Report on Support Given to Personal Assistance Scheme Users by the Personal Assistance Advisor (March, 1992)
- Greenwich Personal Assistance Schemes: Analysis of Financial Viability of Personal Assistance Scheme (July, 1992)
- Greenwich Personal Assistance Schemes: Second Year Evaluation- Interim Report (July, 1992)
- Greenwich Personal Assistance Schemes: Findings from Personal Assistance Scheme Users Survey (September, 1992)

A number of issues which are not discussed here are documented in these further reports and briefing papers. The first year evaluation report, in particular, contains a much more detailed discussion of the development and scope of the Greenwich Personal Assistance Schemes project, the kinds of problems encountered and how these have been addressed. The report on the role of the Personal Assistance Advisor also contains more detailed analysis of the kinds of advice and practical support users need during the different stages of setting-up and managing a Personal Assistance Scheme. Finally, the papers on the financial viability of Personal Assistance Schemes and on the user's survey carried out as part of the evaluation give full details of the findings and cost-analysis which are summarised later in this report.

The changing context of community care

There are two major forces shaping the changes that are occurring in the provision of community care. The first of these is the way in which statutory responsibilities are changing as a consequence of the National Health Service and Community Care Act (1990). The second force is the growing demands of service users to have a voice in the way services are provided to meet their needs. These forces are inter-related for as statutory authorities switch to become purchasers rather than sole providers of services, so users become more vociferous in their demands for a voice in shaping these services, whoever they are purchased or provided by. As one commentator has claimed;-

"It's no longer a question of 'is user involvement a good thing?'. Users' organisations demand it. Legislation requires it". (Peter Beresford Community Care 26 March 1992).

There is a great deal at stake in the context of changing trends in the way support provision is organized and financed; clearly, there is considerable potential for negotiating budget transfers with Local Authorities which would allow much larger numbers of users to control their own support arrangements. Further, the new- Community Care legislation offers greater opportunities for user involvement in the planning and delivery of services.

The forces shaping these changes are not going to go away and hence there is little point in arguing about whether they are a good thing or a bad thing. A much more effective approach is to attempt to influence the changes that are occurring in ways that will enable providers and purchasers to meet their statutory obligations and protect the interests of service users. This will involve far more than single, simplistic solutions such as switching from services to cash. Rather, a variety of new models will be required to meet a whole range of needs and circumstances. Disabled people and their organisations have been in the forefront of developing a range of new models. What follows is a report on one such model, shaped by the twin forces described above and which demonstrates the benefits to all parties of user led initiatives. It is a project developed to enable disabled people to live independently in the community; independence being taken to mean having choice in and control of one's own life.

The Greenwich Personal Assistance Schemes project formally started in November 1989 when the Personal Assistance Advisor (PAA) was appointed. The project was jointly funded by the City Parochial Trust and the Kings Fund for an initial period of 3 years; ongoing funding has since been provided through the joint funding mechanism.

Staffing for the project comprises one full-time post of Personal Assistance Advisor, with support for the post holder provided by staff at Greenwich Association of Disabled People's Centre for Independent living (GAD), where the Personal Assistance Advisor is based. A further important source of support is provided by the advisory group which is made up of local Personal Assistance Scheme users.

The basic aim of the project is to enable more disabled people in Greenwich to live independently in the community by employing their own support workers. This aim is seen as being consistent with current philosophy in Community Care practice (e.g. 'Caring for People' HMSO 1989) and, most importantly, with the demands of disabled people themselves -as expressed by their national. and international representative bodies. The GAD Annual Report 1989/90 reiterates the following resolutions from the United Nations World Programme of Action, and the 1989 Strasbourg seminar on Independent Living which summarise the underlying aim of the Personal Assistance Schemes project:-

“Member states should encourage the provision of support services to enable disabled people to live as independently as possible in the community and in so doing should ensure that persons with a disability have the opportunity to develop and manage these services for themselves.” (UN World Programme of Action)

"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 disabilities, of all ages, on the basis of functional need, irrespective of personal wealth, income, marital and family status " (Strasbourg Seminar on Independent Living)

Reflecting the philosophy described above, the Personal Assistance Advisor's First Year Review stated the project's original aims as follows;-

- to support users and enable further Personal Assistance Schemes to be developed;
- to demonstrate the viability of Personal Assistance Schemes as an option for disabled people;

The Greenwich Personal Assistance Schemes project also aims to provide a positive example to other groups and individuals by demonstrating the possibilities and potential for disabled people to gain more control over their lives through being able to participate fully in home life, work, education, leisure and cultural activities, travel, politics and community activities. Choice and control over how their support needs are met is seen as an essential pre-requisite to this aim.

The Greenwich Personal Assistance Schemes project is seen as an appropriate resource to people in a wide range of personal and domestic circumstances, from those who wish to move out of residential care to those who are already living in the community but require more appropriate support to enable them to maintain their independence. At an organizational level, the project revolves around the role of the Personal Assistance Advisor; this role is primarily defined as offering advice, information and advocacy to people wishing to start up their own Personal Assistance Schemes. A crucial component of this role is advising and (where necessary) assisting people in respect of obtaining funding to set up their own support arrangements. Once funding has been obtained, the Personal Assistance Advisor's role is to provide advice and advocacy on all aspects of setting up and managing Personal Assistance Schemes.

The number of people starting up their own schemes with support and advice from the Personal Assistance Schemes project has increased over the period of the evaluation. Up to November 1990, there were 14 people who had received support from the project and by September 1991 this had increased to around 25. The latest figures compiled indicate that, between April 1991 and April 1992 there were 48 people (30 women and 18 men) running their own Personal Assistance Schemes in Greenwich who had been in contact with Greenwich Association of Disabled People. Of these, 16 are under 40 years of age, 20 are aged between 40 and 59, 7 between 60 and 74, and 4 are aged 75 or over.

Support from the Personal Assistance Advisor

The first year evaluation highlighted that the most significant demands on the Personal Assistance Advisor's resources were advocacy work and providing advice and information. A significant proportion of this work also involved fairly intensive one-to-one support for individual users. At the start of the project, it was anticipated that the main focus for the Personal Assistance Advisor would be on providing initial advice/support to individuals in the process of setting up their own Personal Assistance Schemes; also, that ongoing support on an individual basis would taper off over time. In view of this, it was decided that the second year evaluation should include a closer examination of exactly what kind of support people require at different stages in the process of setting up and managing a Personal Assistance Scheme. This exercise was carried out by the Personal Assistance Advisor filling in a checklist of details relating to each contact with individual people over a three month period. The Personal Assistance Advisor dealt with 75 enquiries from 23 different individuals during this period; nearly 60% of the enquirers were either considering Personal Assistance Schemes or at the early stages of setting up their own scheme. (See table above).

More than half of the enquiries related to finance and/or benefits. Of these, almost two-thirds were from people who were either considering Personal Assistance Schemes or were at the stage of arranging finance; at the same time, the fact that 1 in 4 of enquiries about finance were from people who had been employing their own workers for a year or more illustrates the importance of this kind of support for even the most experienced Personal Assistance Scheme users.

After finance and initial enquiries about Personal Assistance Schemes, the most common type of enquiries related to managing workers and/or employment law; not surprisingly, the majority of enquiries on these issues were from people who had been employing their own workers for less than one year. In contrast to this, the number of enquiries relating to Tax and PAYE were evenly distributed between new and experienced Personal Assistance Scheme users.

Most of the enquiries involved the Personal Assistance Advisor giving out information or advice of one kind or another, and nearly a quarter of the enquiries required some kind of practical assistance (e.g. help with applying to Independent Living Fund).

STAGE USERS WERE AT WHEN CONTACTING THE PERSONAL ASSISTANCE ADVISOR

	(Percent)	
Considering PAS	28	
Arranging Finance	28	59
First time recruitment	3	
Employing for 0-3 months	3	
Employing for 3m – 1 year	20	38
Employing for over 1 year	15	
Don't know	1	
N/A	3	
<hr/>		
(Total)	(100)	

Altogether, over 80% of the initial contacts required some kind of follow-up from the Personal Assistance Advisor (e.g. phoning back, arranging a meeting/visit, or contacting another agency like the ILF). This illustrates how people often require support in a variety of different forms (i.e. written information, advice/discussion, reassurance, etc.). The strength of the Personal Assistance Schemes project is in bringing these various dimensions of support together to provide a flexible and comprehensive resource to users.

While there is a general trend for the number of enquiries to the Personal Assistance Advisor to decrease over time, even people who have been managing their own workers for a year or more continue to need some kind of support with certain aspects of running a Personal Assistance Scheme. This is broadly in line with the pattern of support anticipated at the start of the project, the continuing support to longer-term users does serve to highlight the value of the Personal Assistance Advisor to new and experienced users alike. This also underlines the critical point (which was also highlighted in the recent ILF 'Cash for Care' report)

that, simply transferring funds to users and expecting that the majority will be able to operate their own Personal Assistance Schemes without any advice, information or support at all is completely unrealistic. Rather, for many, it is precisely because they have had access to the right kind of guidance and support (built on disabled people's own experience and knowledge) that they have been able to set-up and run their own Personal Assistance Schemes so successfully.

TYPE OF RESPONSE TO ENQUIRIES FROM USERS

	(Percent)
Information	61
Advice	39
Practical Assistance	23
Advocacy	19
Meeting/home visit	15
Personal support/Reassurance	8
Referral – GAD	8
Referral – Outside agency	0
Refer to PAS sub-committee	1
Other	5

Note: These percentages refer to the proportion out of all the enquiries dealt with which included each of the types of responses listed. Consequently, the figures total more than 100% as some enquiries required more than one kind of response from the PAA.

It is also important to note, however, that some of the support needed by longer-term users results from the way Personal Assistance Schemes are currently funded and the problems this creates for users. The relatively high number of enquiries

about finance (compared to other topics) from long-term users is an indication of this situation. Obviously, if funding arrangements were to be improved then they would need less support from the Personal Assistance Advisor in any case.

User's views

The second year evaluation included a confidential and anonymous survey of all local Personal Assistance Scheme users, 16 of whom contributed information either by interview or by completing questionnaires. Nine of the users participating in the survey are women, and seven are men; their ages range from 32 to 70, the average age being 45. Five of the users are living alone and the rest live with a spouse/partner and/or other relatives. Six are living in owner-occupied homes and the rest in rented accommodation (Local Authority and Housing Association). The main findings from the survey are summarised below.

What type of Personal Assistance Schemes do people have?

The variation in user's personal assistance arrangements shows just how flexible Personal Assistance Schemes can be. Amongst this particular group, 11 have been employing their own workers for over one year, 3 for between three months and one year, and 2 for less than three months. There is also quite a wide variation in the number of workers used; 8 people employ only one regular worker, while 1 person employs 13; the rest all have either two or three. Similarly, 4 people use a single additional worker on an occasional basis while 1 uses up to 9 at different times; most of the others reported using between 2 and 4 occasional workers to supplement their regular arrangements. Average hours worked are 36.5 for regular workers, and 9 for occasional workers. Only 4 people's workers live-in.

Workers are employed to provide a wide variety of assistance. Nearly all of the people in the survey use their workers for housework (15), personal care (14) and assistance with driving and/or using public transport (12). Employing their own workers also means that people are able to have assistance which enables them to participate in social/leisure activities (11) and employment or voluntary work (7). This is a particularly positive aspect of Personal Assistance Schemes, which demonstrates both the degree of choice which this option provides, and the direct and immediate impact on enhancing the quality of disabled people's lives. On a more general level, this also illustrates how Personal Assistance Schemes can benefit society as a whole by allowing disabled people to make a full contribution - as citizens and workers - rather than remaining passive recipients of state welfare and charity.

Use of Community Services

Employing their own workers had also reduced people's dependency on community services. So, while 15 out of the 16 people in the survey had used at least one service in the past, 5 have stopped using other services altogether and the rest use these services less than before. The most marked reductions are for Social Services home help and meals on wheels; 13 people had used these services before setting up their own Personal Assistance Schemes, compared to only 2 currently. (See graph).

Past and present use of services providing personal assistance, on the other hand, remained constant. 5 people are using LB Greenwich Care Attendants and 2 use the Independent Living Scheme. These services are usually kept on to supplement the support provided by people's paid workers and/or to provide 'extra insurance' by allowing users a wider range of resources to cover their support needs. It is clear from the experiences of using these services, however, that this is often more out of necessity than choice. If future funding arrangements for Personal Assistance Schemes were to make provision for occasional back-up support -which is clearly needed - it is likely that the use of these community services would decrease also.

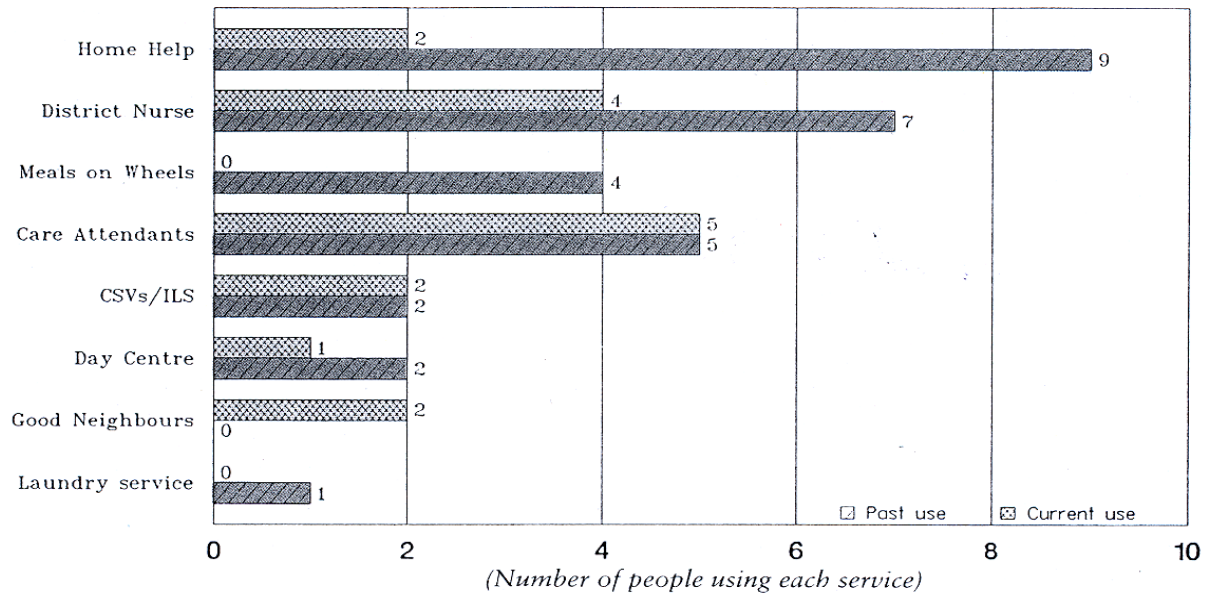
User's views on support from the Personal Assistance Advisor

The user survey also highlights the important role which Greenwich Association of Disabled People had played in helping to get people started with setting up their Personal Assistance Schemes. Out of the 16 people in the survey, 13 reported finding out about the Personal Assistance Schemes option through GAD, or through GAD and another disability organisation. On the other hand, only one said they had found out about Personal Assistance Schemes through a social worker.

9 out of the 16 people in the survey rated the advice and support they had received from the Personal Assistance Advisor as 'very helpful'; 4 could not comment as they had not had any contact with the Personal Assistance Advisor when first setting up their Personal Assistance Schemes; only 2 people said that the support had not been helpful. The quality of support from GAD generally was also highly rated. Regarding support and advice from the Personal Assistance Advisor once they were running their own Personal Assistance Schemes, 8 people had found this helpful and 2 had not. The remainder reported that they had not needed any further support or advice once they had got their Personal Assistance Schemes set up, (Note: The people participating in the user survey are not necessarily the same

people who contacted the Personal Assistance Advisor during the monitoring exercise described in the previous section of this report).

COMPARISON OF PAST AND PRESENT USE OF COMMUNITY SERVICES



The user survey also included questions about particular difficulties or problems people had encountered, both when first setting up their Personal Assistance Schemes, and after they had arranged their funding and recruited their workers. In the setting up stage, the most common problem areas were (not surprisingly) 'organising funding', 'finding suitable workers', 'organising back-up for regular workers' and 'dealing with Tax/NI'. Once they were running their Personal Assistance Schemes, the difficulties most often mentioned by people in the survey were 'managing/disciplining workers', 'dealing with Tax/NI', and 'dealing with the Independent Living Fund'.

As noted earlier, these are precisely the problem areas which the support provided by the Personal Assistance Advisor at GAD is aimed at addressing, through both one to one support and training. Also, half of the people in the survey reported that GAD had been of assistance in helping them to recruit their workers - either through providing advice directly, or by putting them in touch with other disabled people who were able to advise them on the basis of their own experiences.

Summary of user views on Community Services

The evaluation clearly demonstrates that Personal Assistance Schemes are a viable option for a wide range of disabled people who may wish to choose employing their own workers in preference to other service based support options. The criticisms of statutory services on the grounds of inflexibility, lack of choice and control and unreliability are well known and current users of Personal Assistance Schemes were able to express these criticisms.

One user reported her experience of statutorily provided, community based schemes:-

"The home helps were very limited and you had to fit in with them at all times. The Community Care Attendant Scheme is more flexible but you have to accept the times of day that pre-arranged and the same for the length of visits you are limited a lot by the rota system used. If you do not get on with anyone sent to you, you have to accept this, as they don't seem to employ enough people to not send particular individuals (due to sickness/leave etc. of staff) that you do not happen to hit it off with."

Others made similar points about their own experiences:-

"The help was unreliable and not always the appropriate help or at the right time."

"Irregular help therefore not always reliable"

The issue of control was also raised:-

"No control – permanent deep sense of gratitude! Couldn't tell them what I wanted – had to fit in with them."

One major implication when services are perceived to be inflexible, inappropriate or unreliable, is that families are forced to provide the necessary support:-

"I used home helps for personal care from 1980 to 1984. When the Community Care Attendant Scheme expanded to a borough wide service I used them for all my care needs. When I got married my wife took over most of my caring. When the ILF became available we used that for the bulk of my personal care."

"Relied on spouse, children and friends – this restricted activities tremendously."

User's views on Personal Assistance Schemes

In contrast to the experiences described above, the Personal Assistance Scheme model assists in the provision of services in ways that begin to address these criticisms and users often stressed the importance of flexibility and control:-

“The greater flexibility of being able to receive help when and for as long as you want it. The fact you can employ someone you have chosen and get on with. Also the fact that I can employ someone who can fit in with mine and my families requirements and arrangements.”

“My care/services suit my lifestyle – not vice versa!”

And as these and other users made clear, employing their own workers had made a significant impact on the quality of their lives:-

“I cannot begin to describe the difference employing my own care has made to me – Being able to choose has given me freedom in myself.”

Another user stressed that not only had his quality of life improved but he was able to work, while another highlighted that employing her own workers had saved her from going into institutional care;-

“Improved it enormously – allowed me to become fully employed.”

“Without Pas I would have to go into a home. With Pas I can live in my own home without any worries of falling because I've always got someone with me.”

Several people also talked about how controlling their own support had given them the freedom to expand their social and leisure activities, which had often been severely restricted in the past:-

“I can live an independent life – go to the pictures – like anyone else.”

Such support then not only affects quality of life and ability to work but also reduces the obligations on families to provide assistance:-

“I have not needed to rely on my wife all the time – it gives her more time for other things like childcare – it gives me greater independence which leads to a better quality of life.”

“I am a mother again. My son is again a child – he should never have had to empty a commode for his mother – or cook and clean for us both. ... I do not have to use my friends any more. I can go the shops myself – I can go out when I want to – I can sleep upstairs in my own room and get up to go to the toilet instead of sleeping next to a commode. QUALITY OF LIFE – GREAT. I’m alive again – FREE.”

Running your own support scheme including employing your own workers is not something that anyone can take on lightly and in this respect, the Personal Assistance Schemes project set up by Greenwich Association of Disabled People was found to be an invaluable resource:-

“The written material is very useful – Also helpful to talk to other users.”

“Going to the (PAS) meeting gave me support from other users – i.e. confidence.”

“GAD has been the only advice – helped fill in ILF form, sent copies of all our outgoing expenses. Visitor sent (by ILF) was not interested – saying that, if forms were sent, she did not need to know.”

The following quotes sum up the general feelings about Personal Assistance Schemes:-

“Employing my own Personal Assistant has given me the freedom to fulfill the type of lifestyle I wish to follow. I can go where I want when I want I am in total control of making all the choices in my own life. I feel I am much more my own person once again able to put all my abilities to some useful purpose.”

“My life is more interesting, satisfying and rewarding. This means that I can be a full member of the community.”

How much do Personal Assistance Schemes cost?

This section of the report considers financing of the Personal Assistance Scheme option at both the micro (individual) and macro (institutional) levels.

Individual Finance

The people participating in the user survey are paying an average of £189 per week on their Personal Assistance Schemes. 81 % of this cost is financed from ILF payments, 13 % from personal finance (including benefits), and the remaining 6% from other sources, including Local Authority or Joint Finance (see graph below). Regular workers are paid an average of £4.42 per hour, but the average cost of additional cover for when regular workers are unavailable is markedly higher than this at £6.60 (with two people reporting having to pay over £10 per hour for agency workers).

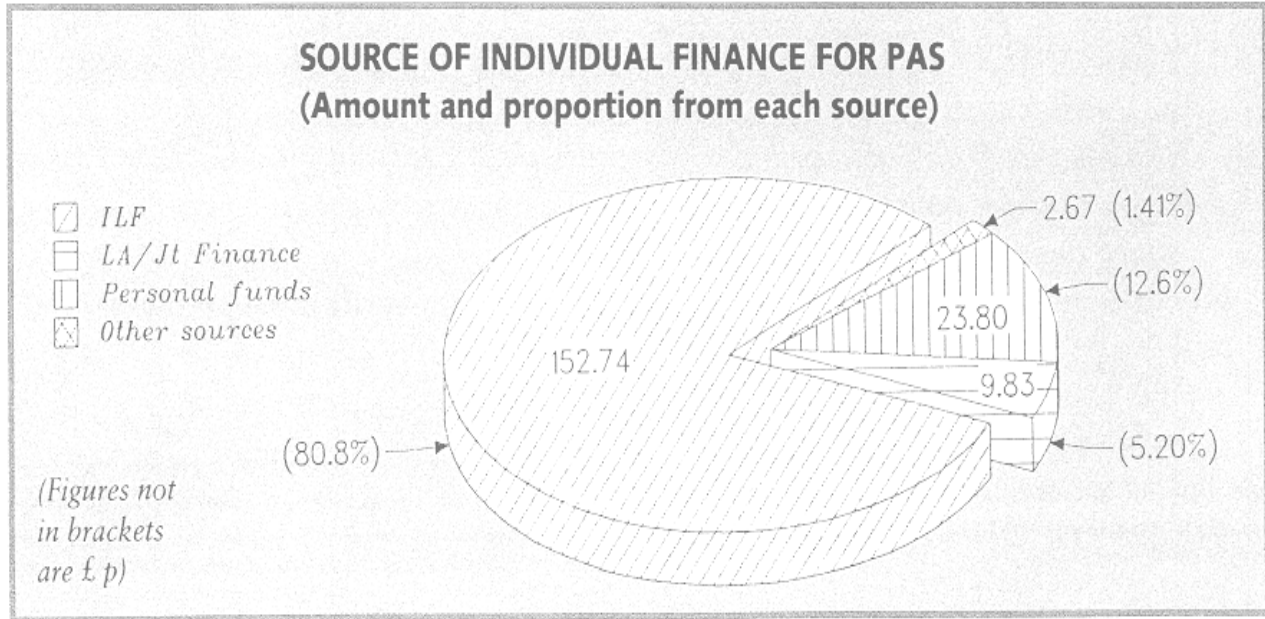
The user survey also included questions about additional costs (apart from worker's wages) involved in setting up and running a Personal Assistance Scheme. For example, the people participating in the survey reported spending an average of £63 on recruitment (advertising, postage, photocopying etc.). Other noteworthy running costs (although not incurred by every one) included the cost of worker's meals (up to) £20 per week), extra telephone costs (an average of £5 per week) and -where applicable - accommodation (up to £70 per week).

Institutional Finance

So far, this report has concentrated on evaluation of the Personal Assistance Schemes option according to the potential for enhancing the quality of disabled people's lives, and empowering them to have choice and control over how their needs are met. At the same time, it is inevitable that the critical issues for institutional funders (i.e. central and local government agencies) will often be the cost-effectiveness of Personal Assistance Schemes as compared to other support options.

Based on standardised costings using financial information provided by Greenwich Social Services and Greenwich Health Authority, it has been possible to compare the costs of a variety of illustrative 'support packages' with providing the same level of support through Personal Assistance Schemes. This shows that the Personal Assistance Schemes option is invariably cheaper than other 'care packages'. (See table on p 11). We have also compiled two actual case studies to

illustrate this further (see Appendix A). These highlight that the Personal Assistance Scheme option is not only cheaper than the statutory services people had used in the past, but also reduces dependency and greatly enhances the quality of users lives.



ILLUSTRATIVE COST COMPARISONS BETWEEN VARIOUS SUPPORT PACKAGES AND PERSONAL ASSISTANCE SCHEMES

	££.pp
Case A:	
Home Help – 4 hours per week	30.32
Care Attendants – 0.5 hours per day (five days)	23.83
Meals on wheels – 6 days per week	18.12
Total weekly cost	72.27
Equivalent PAS (9.5 hours per week) (With support from Personal Assistance Advisor) ¹	42.75 (55.03)
Case B:	
Home help – 2 hours per week	15.16
District Nurse – one hour per week	24.04
Day centre – one day per week	50.00
Total weekly cost	89.20
Equivalent PAS (8 hours per week) (With support from Personal Assistance Advisor)	36.00 (48.28)
Case C:	
Home help – 4 hours per week	30.32
Short term domiciliary care team – 4 hours per week	28.20
District nurse – one hour per week	24.04
Total weekly cost	82.56
Case D:	
One CSV (living in)	144.00
District nurse – one hour per week	24.04
Day centre – one day per week	50.00
Total weekly cost	218.04
Equivalent PAS (35 hours per week) With support from Personal Assistance Advisor)	157.50 (169.78)

1 See Appendix B for details of how support from the PAA is costed

The following table makes a different kind of comparison. This indicates how many Personal Assistance Schemes hours could be purchased for the sort of sums in existing community care budgets, and compares this to how many hours are currently provided by services already available. (Note: the number of hours provided by 3 of the services listed are not shown, as the agencies involved were unable to provide us with this information).

When looking at this data on macro level finance - and bearing in mind disabled people's expressed preference for user controlled services - it is astounding just how many personal assistance hours could be provided/purchased by switching existing monies rather than attempting to generate new sources of funding. For example, as at November 1991 there were 81 people in LB Greenwich in receipt of ILF funding (ILF, 1992); supporting all of these individuals at the financial levels illustrated above would cost only 14.6% of the current Home Help budget.

At the same time, it is important that the conclusions drawn from these figures are not used to support simplistic arguments for blanket solutions, such as 'cash for care'. Rather, they indicate -a) the possibilities for providing the kinds of services that users want and, b) that those services, including the necessary support mechanisms, are not likely to be prohibitively expensive.

ILLUSTRATION OF LEVEL OF PERSONAL ASSISTANCE HOURS WHICH
COULD BE PURCHASED FROM EXISTING COMMUNITY CARE BUDGETS
IN GREENWICH

LA/DHA service	1991/92 budget (£)	No. of hours Service	Equivalent PAS Hours
Home Help service	5,050,096	655,912	1,045,569
Care Attendant Scheme	347,000	36,400	71,843
Independent Living Scheme (1990/91)	82,330	(not known)	17,046
Meals on wheels service	787,600	N/A	63,064
Short term Domiciliary Care	140,000	15,600	28,986
Sandpit Day Centre	540,000	(not known)	111,801
District Nursing service	2,500,000	(not known)	517,598
Totals	9,447,026	-	1,955,907

Note: Equivalent Personal Assistance Scheme hours are calculated on the basis of a cost of £4.50 per hour plus a weighting of £0.33 per hour for support provided by the Personal Assistance Advisor at GAD (i.e. £12.28 per person per week/average of 36.5 PAS hours used per person per week).

POLICY IMPLICATIONS

The success of Personal Assistance Schemes in allowing users to control how their support needs are met, provides a good model for the empowerment of disabled people by demonstrating that -given genuine choice and adequate resources- disabled people are able to exercise control over their own lives and reduce for themselves their enforced dependency on inadequate services.

Bearing in mind that the finance for employing their own workers comes, mainly, from the Independent Living Fund and that the Fund itself acknowledges that it is unable to provide help and support in employing staff (Kestenbaum, 1992), Personal Assistance Scheme projects like the one evaluated here can clearly play an important role in this crucial area, giving people both the confidence and the skills to take on such tasks and responsibilities. Such models will have increasing relevance to Social Services Departments as they take on responsibility for new ILF clients in April 1993.

In the evaluation of its own services, the ILF noted that some of its recipients found the prospects of taking on such responsibilities daunting and produced comments such as "it's all down to me" and "thrown in at the deep end". Not only that but some ILF recipients felt that support from their social services was inadequate and only involved "pointing out a list of agencies in the Yellow Pages". The concern that many disabled people feel about what will happen when social services become the lead agency in community care was expressed by some of the Greenwich Personal Assistance Scheme users also;-

"I do hope that we can continue to employ our own helpers. I am very frightened of a return to care workers provided by Social Services. Everyone is different and so are the people you can work with. If an able bodied person employs your carer for you -well it does not work that way."

This report has suggested that developing independent living options like Personal Assistance Schemes is not just morally desirable and professionally appropriate, but also offers the possibility of providing more cost effective and efficient services through switching from the overproduction of welfare services that people don't want or need and the underproduction of those that they do, to a situation where the services that are produced and purchased by statutory providers are precisely the services that users want and need.

This assertion is not merely an act of faith but of economic necessity. Clearly society is no longer able or prepared to fund dependency creating services and the onus is on us all to develop services which facilitate independence. Recently the

USA has embarked on an even more radical course than just attempting to restructure welfare services, through the passage of comprehensive anti-discrimination legislation (The Americans with Disabilities Act 1990). That the Act became law was more to do with the economic rationality underpinning it than any moral concerns;-

"The ADA presents an opportunity to turn the corner on policies promoting welfare-like dependence and to develop instead supports for independence in the context of working, living and recreating in the mainstream. In this sense, implementing the ADA is an opportunity to contribute to an improved economy. When persons with disabilities give up public subsidies for jobs, they leave funds in the public coffers. When they become tax- payers, they contribute directly to public treasuries. When persons with disabilities become consumers in the marketplace, they strengthen the economy". (West 1992.333)

User controlled Personal Assistance Schemes offer similar possibilities in less grandiose but no less important ways and should be developed rapidly as a major mechanism for developing new approaches to community care.

In our view, the Personal Assistance Scheme provided by the Greenwich Association of Disabled People is one model of providing services with disabled people which facilitates their independence and which will enable them to make substantial contributions to the lives of their communities as workers, tax payers and active citizens. As such it is a model we would commend to all agencies charged with responsibilities for providing community based services.

References

- ILF(1992) *Independent Living Fund -Annual report for 1991*, Independent Living Fund
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Appendix A

Two Case Studies

The comparative cost analysis outlined earlier in this report demonstrated that Personal Assistance Schemes are invariably cheaper than existing service based options. The report has also highlighted that, the Personal Assistance Scheme option reduces dependency on statutory services and gives users much greater control over their own lives.

These key themes - reducing dependency and cost-effectiveness - can be illustrated further by two brief case studies using data from the user survey carried out as part of the evaluation.

CASE 1

The first of these illustrations is based on the experiences reported by a 39 year old man who lives with his partner in a Housing Association flat. He employs two personal assistants using funding from both the Independent Living Fund and the Local Authority. The personal assistants live in a flat above his and each works a regular 35 hour week.

Prior to setting up his own Personal Assistance Scheme, he had used a combination of LB Greenwich Care Attendants, Community Service Volunteers (also funded by the Local Authority), and the Community Nursing service for meeting his personal assistance needs. In answer to questions about any problems he had experienced with these services, he gave a quite extensive list;-

"Yes. Not being able to get up when I want. Having to go to bed at other people's convenience. Not able to cook proper food -have to get ready made food. Not able to go out when I wanted. "

Another problem he had experienced with the LB Greenwich Care Attendants and District Nurses was that, neither service provided any cover outside of their normal hours. This meant *"always being in difficulty if an emergency occurs"*. Now, with having two personal assistants, cover is always available -*"the other helper does it all"*.

Since employing his own workers, he has stopped using any statutory services whatsoever. The workers are used for personal assistance, cooking, housework, driving, assistance with social and leisure activities, and help at work.

He is much more satisfied with this arrangement than having to rely on statutory services which he has now stopped using altogether;-

" I am independent now since employing my own PAs. Its given me the chance to have my own choices in life. "

Regarding his experience of setting up and running a Personal Assistance Scheme, the most significant problem he had found in the early stages was *"finding out how much you can ask a helper to do -within reason"*, although he had been able to work this out over time by *"trial and error"*. Generally, he feels that he now has *"better organisational skills with the experience I've had since employing PAs - now I have better skills."* Consequently, he feels that he no longer needs any advice from the Personal Assistance Advisor, although he did emphasise that this had been important when he was first starting up;- *"I only needed advice on the budget -intelligent enough to do everything else myself."*

The cost of this man's Personal Assistance Scheme is £331 per week; this is financed by £290 from the ILF, with the balance being paid by the Local Authority. This is £48 cheaper than the arrangements he had before setting up his Personal Assistant Scheme as shown below;-

	£
2 live-in CSVs	288
District Nurse (1 visit per week)	24
LB Greenwich Care Attendants 7 hours per week	67
Total cost	379
2 PAs working 35 hours per week ((@£4.30 per hour)	301
Other costs (insurance etc..)	30
Total cost	331

CASE 2

The second illustration is based on the experience of a 53 year old woman living with her husband and children in their own house. She employs one regular personal assistant for 30 hours per week and also has a rota of occasional workers whom she employs as and when required. All of her personal assistants live-out. The workers are used for personal assistance, cooking, cleaning, transport, assistance with social and leisure activities, and help at work.

Prior to setting up her Personal Assistance Scheme she had used the Community Nursing service, LB Greenwich Care Attendants, Home Helps, and Meals on Wheels. She also reported having up to 60 hours per week 'informal support' from her family. Although three different services were involved, the support she received was inadequate because she had *"only social services provision -plus the family"*.

As with most of the people in the survey, she also highlighted how the inadequacies and inflexibility of statutory services had restricted her choices"-

" Yes -not able to do what I wanted when I wanted to. Social activities much less (than now)."

Since starting her own Personal Assistance Scheme, she has stopped using the District Nursing, Home Helps and Meals on Wheel services, although she still uses the LB Greenwich Care Attendants (6 hours per week) as part of her back-up system.

For this woman, employing her own personal assistants and having an adequate and reliable back-up system means *"much more flexibility and the ability to do what I want when I want to"*. She also emphasised that, this flexibility extends far beyond just having adequate and acceptable personal assistance arrangements, and allows her to make a much more active contribution to society;-

"My life is more interesting, satisfying and rewarding. This means that I can be a full member of the community."

Regarding help and advice from the Personal Assistance Advisor, this woman had already started employing her own workers before the post was set up. However, she has made use of this resource *"for odd things since"*, particularly *"advice on a pay rise (i.e. for her workers) and extra funding for deterioration, and statutory sick pay"*. She added that, *"finding out about what the ILF would allow for use of*

the money" had been difficult when she was first starting-up, so would have found advice on that useful if it had been available.

Her Personal Assistance Scheme costs £1.75 per week; this is financed by £170 from the ILF and £5 of her own money. The total cost of her present support arrangements is £202 a week (including the cost of the LB Greenwich Care Attendants). As she now uses less hours from the Care Attendants, there is an overall saving of £20 as shown below;-

	£
District Nurse (2 visits per week)	48
LB Greenwich Care Attendants 12 hours per week	114
Home Help (6 hours per week)	45
Meals on Wheels (5 days per week)	15
Total cost	222
1 PA working 30 hours per week (@£4 per hour)	120
Other costs (insurance etc..)	25
LB Greenwich Care Attendants 6 hours per week	57
Total cost	202

Appendix B

COSTINGS FOR SUPPORT TO PERSONAL ASSISTANCE SCHEME USERS PROVIDED BY GAD:

	£
Expenditure 1991 (PAS)	17,800.00
Consultancy (inc users)	2,500.00
Total annual cost	20,300.00
Weighted to 1992 prices	21,822.00
Annual cost/Minimum no. users supported (25)	872.90
Annual cost/Maximum no. users supported (54)	404.12
Average per person per year (Min+Max/2)	638.51
Average per person per week	12.28

Note: The minimum/maximum numbers of users which could be supported by present Personal Assistance Advisor post are based on detailed analysis of Personal Assistance Advisor's workload. (See - Greenwich Personal Assistance Schemes: Report on Support Given to Personal Assistance Scheme Users by the Personal Assistance Advisor, March 1992).