

COMMISSIONING INDEPENDENT LIVING

A guide to developing personal assistance
schemes and support services



Etienne d'Aboville



THE PRINCE OF WALES'
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Published by King's Fund Publishing
11-13 Cavendish Square, London W1M 0AN

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ISBN 1 85717 096 2

Graphic design and production Shapes Design Consultants

Printed in Great Britain

ACKNOWLEDGEMENTS

Information for this publication was drawn from a variety of sources, including published documents, reports from the Living Options Partnership projects and Network Areas, and from those involved in commissioning and operating personal assistance schemes and support services. I am grateful to all who contributed in this way.

I am also grateful to Jenny Morris for furnishing some useful references and background materials. Finally, I would like to thank Sheila Fletcher of Living Options Partnership and Janice Robinson of the King's Fund for their helpful comments on earlier drafts of this document.

A note on terminology

Independent Living

A set of values and beliefs which emphasise disabled people's right to make their own choices, control their own lives and participate in all aspects of society on equal terms with non-disabled people.

Independent Living scheme

An arrangement which enables disabled people to obtain support in carrying out daily activities and which adheres to the basic principles of the Independent Living movement, i.e. maximising choice and control.

Informal support

Support received on an unpaid basis from friends or relatives.

Personal assistant

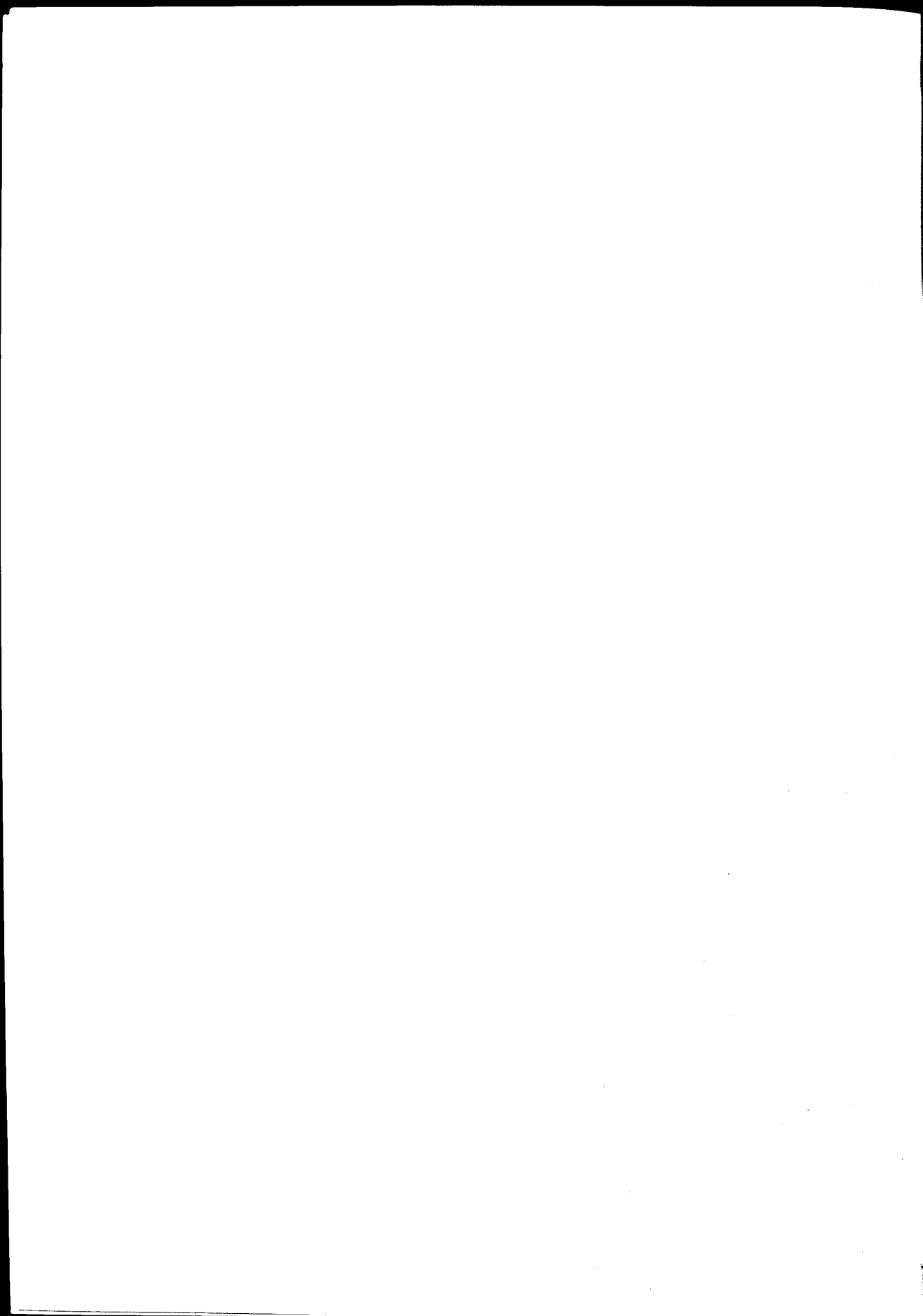
A person employed by a disabled person to provide help with personal care, domestic, social, educational or employment activities.

Personal assistance scheme

An individually tailored arrangement which enables disabled people to act as their own care managers, control their own budgets and employ and manage personal assistants.

Personal assistance support service

A service which provides disabled people using personal assistance schemes with services such as advocacy, information and training, payroll, assistance with recruitment and emergency cover.



Introduction

For nearly 15 years increasing numbers of disabled people in the UK have been working with allies in the statutory sector to set up schemes which enable them to have greater choice and control over their lives. During the past decade, the rapid growth in the Independent Living movement and the popularity of the Independent Living Fund contributed to a climate of demand that Independent Living schemes should become part of mainstream provision. Recent reforms in the way health and social services are organised and delivered have presented a framework within which this can be achieved.

As the period of turbulence and confusion which has accompanied the NHS and Community Care reforms in many areas begins to settle down, the opportunities which are offered by the split in purchasing and providing responsibilities are becoming clearer. Many local authorities are already seizing these opportunities to work in partnership with disabled people and their organisations. They are setting up schemes which offer individual disabled people genuine control over the way their support needs are managed.

Independent Living schemes are a positive choice for all concerned. They meet many disabled people's needs in a way which traditional services have often failed to do and they offer commissioners the opportunity to purchase quality services which have an immediate and tangible impact.

A number of challenges lie ahead for health and social services commissioners: they need to find new ways of working with disabled people as partners in planning and developing Independent Living services which genuinely empower rather than create dependence and in devising new methods of assessing the quality of services, focusing less on the outputs of services and more on the outcomes for users. The prospect of changes in the law prohibiting direct payments to users offers authorities further opportunities to maximise user control and to simplify administration.

This document is aimed primarily at senior managers in health and social services who have responsibility for commissioning services for adults with physical and sensory impairments and at people with responsibility for hands-on purchasing (e.g. care managers). It should also prove of interest to service providers in the statutory and independent sectors and to disabled people themselves. Its purpose is to offer some guidance on how to take maximum advantage of opportunities for purchasing and developing personal assistance schemes and support services.



INTRODUCTION

Chapter 1 explains what Independent Living and personal assistance are and what they mean to disabled people. Chapter 2 suggests how commissioning personal assistance schemes can help health and social services authorities meet their legislative responsibilities and put policy objectives into practice. Chapter 3 outlines some important factors in planning schemes. Chapter 4 looks at the options for enabling users to control the finance for schemes. This chapter also assesses how back-up and support services can be provided, and considers some key issues in implementing schemes. Chapter 5 examines how the performance of schemes can be assessed, and Chapter 6 looks at how schemes and support services may be financed.

This document draws on published material and, most importantly, on the experience gained by agencies and users involved in existing schemes, including those areas which took part in the Living Options Partnership projects and Network. The schemes highlighted are real examples of initiatives around the country. However, the examples based on individuals are intended for illustration only and do not refer to actual individuals.



1 What is Independent Living?

Independent Living is a set of values and beliefs which emphasise disabled people's right to make their own choices, control their own lives and participate in all aspects of society on equal terms with non-disabled people. Personal assistance schemes enable disabled people to organise and control the support they need to live independently.

Although the concept of Independent Living is not a new one, its values and principles may not be clearly understood by those more familiar with traditional ways of providing services. Health and social services commissioners need to be clear about:

- the principles and values underlying Independent Living
- what personal assistance is and what it means for disabled people
- who can make use of personal assistance schemes.

➤ PRINCIPLES AND VALUES OF INDEPENDENT LIVING

The philosophy of Independent Living is based on four key assumptions:

- all human life is of value
- anyone, whatever their impairment, is capable of exerting choices
- people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives
- disabled people have the right to fully participate in society.¹

Independent Living is closely associated with a social model of disability, with the rapid growth in disabled people's own organisations and with an increasing pressure for equal opportunities and civil rights legislation. The social model of disability assumes that it is the barriers which people with impairments encounter in society which disable them, rather than the impairments themselves. For instance, it is the lack of appropriate support services, not the inability to get dressed without help, which disables an individual who needs to get up in time to go to work.

Independent Living therefore is not about being able to carry out activities such as washing and dressing without assistance. It is about exercising choice and control over decisions and opportunities which non-disabled people take for granted.



WHAT IS INDEPENDENT LIVING?

'Independent Living is the ability to decide and to choose what a person wants, where to live and how, what to do and how to set about doing it.

These goals or decisions about a person's life and the freedom to participate fully in the community have been and will continue to be the essence of Independent Living.

It is also the taking and establishment of self-control and self-determination in the total management of a person's everyday life and affairs.'

British Council of Organisations of Disabled People

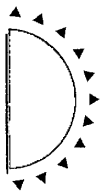
Putting these broad principles into practice involves many aspects of disabled people's lives. Disabled people have identified seven fundamental needs:

- **information** to enable them make choices
- **counselling** to help them make those choices
- **housing** which is suitable, accessible, well-located
- **technical aids** or enabling equipment
- **personal assistance** when they need it
- **transport** to function in society
- **access** to all public buildings/amenities.²

While all these are important, of central importance to those who need them are services which provide help with personal, domestic, social and sometimes educational or employment activities. For many disabled people, having control over how this type of support is provided is what makes the critical difference in enabling them to lead an independent lifestyle.

The term 'Independent Living scheme' normally refers to a scheme which provides help with these kinds of activities. However, schemes differ widely in the way that support is arranged, funded and managed. For instance, some disabled people employ workers themselves, others use workers employed by other agencies. Chapter 4 considers the options in greater detail.

The term 'personal assistance' is increasingly being used to describe arrangements whereby the worker is employed directly by the user rather than by an intermediary agency. Personal assistance schemes also tend to be characterised by one-to-one working, rather than users drawing on a pool or bank of workers.



This publication is concerned primarily with the commissioning of personal assistance schemes, although other kinds of Independent Living scheme are briefly considered.

➤ **PERSONAL ASSISTANCE AND WHAT IT MEANS FOR DISABLED PEOPLE**

Personal assistance schemes offer the user flexibility and control because it is the user who decides:

- who the workers are
- when they work
- what they do.

In the simplest form of personal assistance scheme it is the user who:

- recruits, interviews and appoints workers
- agrees the contract of employment
- pays workers.

Although retaining complete responsibility for all aspects of the administration of a scheme may be one way of ensuring control, the distinction between management and administration functions is an important one. Providing effective personal assistance support services can relieve the user of some of the administrative duties (e.g. payroll), and in turn can increase the number of people who are able to use the scheme. A key challenge for those developing services is to promote and to safeguard the control users have over schemes while making them easy to use.

The impact that using personal assistance schemes can have upon the quality of disabled people's lives is becoming increasingly well documented.³ At its best, personal assistance can enable disabled people to:

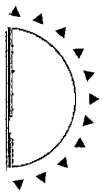
- live in their own home
- engage in personal and social relationships on equal terms
- fulfil their role as a parent or partner
- have access to education or become economically active
- participate in the social and political life of the community.

By opening up access to a full range of life choices, personal assistance can help disabled people transform their social identity and reclaim their citizenship.

Karen's story

Karen is 25 years old. For most of her life, her need for help with mobility, communication and in carrying out everyday activities was met by her parents or at the special schools and colleges she attended. Following an initial assessment, the care manager put Karen in contact with the personal assistance support service which is run by a local disabled people's organisation. The Independent Living adviser helped Karen cost out and set up a package of support through which she employs two full-time personal assistants. Funding for the scheme comes from the Independent Living (1993) Fund and from the social services department, which pays £200 per week into a separate bank account via the personal assistance support service.

The arrangement has enabled Karen to move into her own flat and to develop her skills as an artist by attending a part-time course at a local college.



➤ WHO CAN MAKE USE OF PERSONAL ASSISTANCE SCHEMES?

Most existing users of personal assistance schemes are younger people (aged 16–64) with physical impairments. Some local authorities have recognised that a wider range of people has the potential to benefit from controlling their own support arrangements and should be enabled to do so. They have set eligibility criteria to include some or all of the following groups of people:

- older people (65 or over)
- people with learning difficulties
- people who are HIV positive or who have AIDS
- people with mental health problems.

The basic principles underlying personal assistance schemes may also be of relevance in meeting the needs of people with sensory impairments. For instance, a blind person who requires help with reading correspondence, cleaning, shopping and mobility may value the flexibility offered by employing one or two workers to provide a range of support.

The kind of support services which a scheme offers will influence who is willing and able to use it. In planning a personal assistance scheme therefore it is important that clear decisions are made at an early stage about whom a service is aimed at, and that the rationale behind such decisions is explicit.

Enabling equal access

Some groups have found it especially difficult to access services which meet their individual needs. For instance, Black disabled people (particularly those for whom English is not their first language) may benefit from employing personal assistants who understand their culture or their language. Lesbian and gay disabled people may also value being able to choose their own workers. Specific outreach work will be required to ensure that such groups have equal access to these opportunities.⁴

Wiltshire's experience

The Wiltshire Independent Living Fund (WILF) was established using ring-fenced Independent Living Transfer monies to give disabled people the funding to purchase their own personal assistance packages.

Because the take-up of services by the established Black community had been limited, the Living Options Partnership project set out to increase Black disabled people's access to WILF.

An outreach worker was employed to identify Black disabled people needing personal assistance and to help them develop appropriate packages of support. Despite some initial difficulties in locating Black disabled people eligible for the scheme and in finding appropriate people to do the assessments, increasing numbers of users have now been recruited. For example, one Asian disabled person now employs an African Muslim friend to provide personal assistance. The project is also negotiating with a private care agency to help recruit workers from particular communities if Black disabled people prefer this approach to meeting their needs.

Knock-on effects of the project have included:

- the identification of unmet health needs
- the introduction of ethnic monitoring in social services
- the opening-up of direct lines of communication between the director of social services and representatives of the Black community
- a higher priority for Black disabled people on the agenda of the local user network.

WHAT IS INDEPENDENT LIVING?

KEY POINTS

- Independent Living is essentially about choice and control, equal opportunities, empowerment and autonomy.
- Commissioners need to engage in a dialogue with disabled people and their organisations to agree how these principles can best be applied in developing any new service.
- Personal assistance schemes can dramatically improve the quality of service that disabled people receive.
- The benefits of using personal assistance are widely applicable to many groups of people – decisions about eligibility should be based on explicit criteria.
- Specific work with marginalised groups can give them access to Independent Living opportunities.



2 Why commission personal assistance schemes?

When planning how to meet the personal assistance needs of disabled people, health and social services commissioners will need to be clear about their aims. These aims might include:

- meeting legislative requirements
- commissioning high-quality services
- meeting intensive or complex support needs
- offering choice and meeting a wide range of need
- making the most effective use of resources.

➤ MEETING LEGISLATIVE REQUIREMENTS

When commissioning personal assistance schemes, health and social services agencies will have regard to their obligations under existing legislation and guidance.

Social services authorities

Section 47(1)(a) of the NHS and Community Care Act 1990 provides that local authorities should carry out an assessment of need for any individual who may be in need of community care services. The *Summary of Practice Guidance* defines 'need' as 'the requirement of individuals to enable them to achieve, maintain or restore an acceptable level of social independence'.⁵

The Guidance also states that care management and assessment should be 'adapting services to meet needs rather than fitting people into existing services, and dealing with the needs of individuals as a whole rather than assessing needs separately for different services'.⁶

Section 2(1) of the Chronically Sick and Disabled Persons Act 1970 provides that social services authorities have a duty to arrange to meet a range of needs, including the need for 'practical assistance in the home' as well as recreational and educational facilities and holidays if the disabled person is assessed as needing them.



The Policy Guidance issued to social services departments refers to the objective of ensuring that service provision should 'as far as possible, preserve or restore normal living'. It also urges social services departments to give priority to 'support for the user in his or her own home' over admission to residential care.⁷

The Policy Guidance also states: 'It may be possible for some service users to play a more active part in their own care management, for example assuming responsibility for the day-to-day management of their carers may help to meet the aspirations of severely physically disabled people to be as independent as possible.'⁸

The guidance on needs-led assessment advises social services authorities to consider whether their approach to assessment and care management enables people to 'live a full life in the community with equal opportunity for privacy and dignity' and 'be in charge of their own lives and make decisions including decisions to take risks.'⁹

Health agencies

Much of the above guidance also applies by implication to health agencies. Certainly, where appropriate, health agencies are expected to work closely with social services authorities in carrying out assessments under community care legislation and in ensuring that proper provision is made for people leaving hospital.

The Patient's Charter includes a standard that, before being discharged from hospital, a person can expect 'a decision to be made about how to meet any needs [s/he] may continue to have'.¹⁰ Health agencies will also wish to ensure that this standard is applied to disabled people leaving hospital.

Needs-led assessments, encouraging users to be their own care managers, enabling choice and control and achieving 'an acceptable level of social independence' – all of these policy and legislative requirements are met by personal assistance schemes which provide individually tailored packages of support.

➤ COMMISSIONING HIGH-QUALITY SERVICES

By definition, high-quality services are services which meet the expressed needs of users. There is considerable evidence that personal assistance schemes are a preferred option for many disabled people over direct service provision, informal support provided through friends or relatives, or residential care.¹¹



WHY COMMISSION PERSONAL ASSISTANCE SCHEMES?

Personal assistance users have defined the advantages of schemes in terms of:

- **flexibility** – the range of tasks which workers can carry out
- **choice** – being able to choose workers who understand individual requirements and lifestyles
- **control** – being able to determine how support is provided and to make changes when necessary
- **reliability** – having workers turn up when expected
- **mobility** – avoiding the need to remain at home to receive a service
- **simplicity** – reducing the number of different workers needed.

It also seems likely (although this is more difficult to document) that operating a personal assistance scheme will have a positive impact on overall health with a consequential reduction in the use of health services.

Personal assistance schemes, then, fulfil users' own criteria for high quality services and result in higher levels of user satisfaction.

Frances's story

Frances has severe pain from arthritis which fluctuates according to her level of activity. Frances used to receive visits from the home care service, meals on wheels and the district nursing service to help her with shopping and cleaning, cooking and personal care. She used to get out very little but frequently had to go into hospital for short spells of treatment when the pain and stiffness became too severe.

Frances applied to join the local personal assistance scheme and now has a budget which she uses to pay two part-time personal assistants who provide all of the help she needs. She is now able to go shopping and visit friends and goes swimming twice a week. As a result, she has been able to reduce the amount of medication she needs and spends less time in hospital.

➤ MEETING INTENSIVE OR COMPLEX SUPPORT NEEDS

The options facing disabled people with substantial personal assistance needs are few: residential care; long-stay hospitals or rehabilitation units; reliance on informal support provided by family or friends; or use of a fragmented range of services.

WHY COMMISSION PERSONAL ASSISTANCE SCHEMES?

Personal assistance schemes offer a more coherent and integrated approach which many disabled people find considerably more satisfactory. Where health and social services are working effectively together, personal assistance schemes can also offer opportunities for disabled people who have health-related needs, such as the need for specialist nursing or physiotherapy services, to purchase these as part of an integrated package of support.

➤ MEETING A WIDE RANGE OF INDIVIDUAL NEEDS

Meeting the needs of Black populations or lesbian and gay disabled people can be difficult as the attitudes and understanding of workers are all-important in determining the user's experience of the service. Personal assistance schemes enable users to recruit workers who understand their individual needs and with whom they feel comfortable in carrying out personal tasks or engaging in social activities.

➤ MAKING THE MOST EFFECTIVE USE OF RESOURCES

As well as offering disabled people a higher-quality service, there is growing evidence that personal assistance schemes can be a more cost-effective option than direct service provision.¹² Recent research suggests that personal assistance schemes may be between 30 and 40 per cent cheaper than providing a comparable amount of support through direct service provision.¹³

Personal assistance schemes may also enable disabled people who are blocking expensive hospital or rehabilitation unit beds to be discharged into a more appropriate environment. For instance, the estimated cost of a bed in a specialist spinal injuries unit is between £250 and £500 per day.

KEY POINTS

Personal assistance schemes:

- are an effective way of meeting legislative and policy requirements
- offer wide-ranging benefits to users, compared with direct service provision
- can achieve outcomes for marginalised groups which improve on existing services
- offer the potential for health gain
- can be more cost-effective than direct service provision.



3 Planning personal assistance schemes

It is essential that disabled people and their organisations are directly involved in all stages of development of a personal assistance scheme. This means involving users in planning, implementation, monitoring and evaluation. Drawing on disabled people's own experience will be invaluable in ensuring that the services which are developed are appropriate and effective.

In order to be sure of making the right choices, commissioners will need to:

- **identify key stakeholders and open a dialogue**
- **work with disabled people to assess the options**
- **agree priorities and establish clear aims.**

➤ **IDENTIFYING KEY STAKEHOLDERS AND OPENING A DIALOGUE**

It is important that disabled people become partners in planning and developing personal assistance schemes at the earliest possible stage.

Ideally, a range of users and potential users should be involved, including the following:

- local organisations of disabled people
- users of existing services (e.g. domiciliary care)
- people in residential care homes, long-stay hospitals or rehabilitation units
- disabled people currently receiving informal support from family members
- people with a variety of impairments
- people who experience multiple discrimination (e.g. Black disabled people, lesbian and gay disabled people).

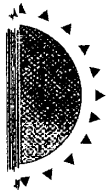
Most existing personal assistance schemes have been initiated by disabled people and their organisations. However, commissioning agencies will need to make the first move in many areas. Social services authorities have a central role to play in assessment and in the funding and co-ordination of schemes. They are also well placed to take the lead in bringing together other agencies, such as health, education, employment and benefits, to explore how they can contribute to a more integrated Independent Living strategy.



Some health and social services authorities have been able to take advantage of existing user involvement mechanisms, such as a user forum or a task group linked to a joint commissioning group, to kick-start the planning process.

Where such user involvement mechanisms are not well developed, or where there are no local groups or organisations of disabled people, extra efforts will be required. It may be useful to arrange a public meeting, conference or seminar where ideas and options can be discussed and where individuals can be identified to take part in more detailed work, for instance, by participating in a steering group or working group. At the same time, disabled people can be supported and facilitated in establishing representative groups which can become part of the future strategy.

Northamptonshire's Joint Commissioning Strategy



Northampton's county-wide strategy group includes the social services department, family health services authority, Northampton Council for the Disabled and the health authority, which has taken the lead role. The group adopted the Living Options principles to underpin the work and established eight task groups supported by a user involvement steering group comprising 12 disabled people. One of the task groups focused on community and personal support. The task groups included users and statutory and voluntary sector representatives. They were given a remit to consult with users, to review existing services and to develop recommendations for future action. Outreach work was carried out using a consultant and link workers to consult with members of Black and ethnic minority communities. In all, over 300 people were consulted and 14 local meetings were arranged. Questionnaires and telephone and one-to-one interviews were also used. A stakeholder day was held to review the findings of the consultation process and to enable further opportunities for input.

The task group on community and personal support made a variety of recommendations and identified the need for:

- a flexible personal assistance scheme offering disabled people a range of options
- user-led advocacy in setting up packages of support
- access to 24-hour emergency cover.

Implementation groups were established to draw up service specifications and turn the recommendations into action.

➤ **WORKING WITH DISABLED PEOPLE IN ASSESSING THE OPTIONS**

In assessing the available options it may be desirable to consult potential users of the service and/or to review existing provision. One way to do this is to commission a user consultant to gather additional information on needs and preferences. For instance, do users want to employ workers directly or would they prefer to use agency workers? Is a recruitment or a payroll service a priority?

A variety of methods can be used: workshops examining what users want from a scheme; semi-structured interviews; questionnaires; or any combination of the above. In general, collective modes of consultation offer some advantages over individual methods in that they enable a fuller exchange of ideas and information about the possibilities. Combined with information from assessment records, consulting in this way could also help give an indication of the likely level of demand for any new service.

Where there are a number of user groups, social services authorities may wish to consider the benefits of resourcing them to form a local network. This should enable a more coherent approach to consultation and joint working. By pooling expertise it may also open up opportunities for delegated service provision.

The expertise of users is an essential ingredient in developing appropriate services and should be valued as such by professionals. One way of recognising this principle is by paying individual users and groups for their input.

➤ **AGREEING PRIORITIES AND ESTABLISHING AIMS**

It is essential that users and professionals spend time considering how users' aims and professionals' purchasing criteria can both be satisfied.

Purchasing criteria might include:

- **accessibility** – how easy will it be for users to access the new service?
- **equity** – will it be equally accessible to all sections of the community?
- **appropriateness** – will it offer users the level of choice and control they desire?
- **efficiency** – is the scheme cost-effective (bearing in mind that user definitions of 'effective' are what counts)?

PLANNING PERSONAL ASSISTANCE SCHEMES

- **acceptability** – are the administrative and legal implications clear and workable?
- **effectiveness** – will it have the desired impact on users' quality of life?

From principles such as these it should be possible to agree a clear set of aims for the service. These could include that:

- the service should be simple, flexible and offer the user the maximum level of control
- the service should be equally accessible to all sections of the community
- the assessment process should focus on self-assessment
- users should be able to choose how much responsibility they assume for employing and managing personal assistants
- users should be able to change the arrangements as their experience grows or their needs change
- procedures for ensuring accountability should be simple, straightforward and non-bureaucratic
- complaints procedures should be accessible and non-threatening

The more explicit these aims can be made, the easier it should be to agree which model is most likely to achieve the desired result. Clear targets can then be set out together with appropriate timescales and responsibilities.



KEY POINTS

- Disabled people and their organisations must be closely involved in planning and developing the service.
- Where representative organisations are not well developed, they should be resourced and promoted as part of an overall Independent Living strategy.
- Clear aims should be established which reflect Independent Living principles, the views of local disabled people and key purchasing criteria.
- Purchasing plans should be informed by predictions of future demand based on records of assessments and unmet need. These should be documented in community care plans.

4 Implementing personal assistance schemes

Two key issues have a significant impact on the quality of service which personal assistance users experience and these need to be resolved before a scheme can be implemented:

- how to give users purchasing power
- how back-up and support services are provided.

➤ GIVING USERS PURCHASING POWER

Giving users control over how to spend personal assistance funding is both an important principle in empowering users and a practical way of enabling flexibility. Of course, purchasing power is most effective when there is a range of options to choose from. Services are needed which enable users to choose whether to recruit and employ their own workers, whether to take on the administrative responsibilities of being an employer or whether to use independent providers. In practice, many users may wish to minimise their involvement with the practical details of using personal assistants and of handling budgets, but this should be a deliberate choice rather than an administrative expedient.

Personal assistance users can be given control over a personal assistance budget in two basic ways:

- direct payments
- indirect payments.

Direct payments

Direct payments are cash grants made directly to disabled people to enable them to buy in personal assistance.

Local authorities in England and Wales have been prohibited from making direct payments because of restrictions within the National Assistance Act 1948, the Health Services and Public Health Act 1968 and the National Health Service Act 1977. However, a number of authorities had operated direct payments schemes until the Government's guidance on implementation of the NHS and Community Care Act 1990 drew attention to their legal status.



IMPLEMENTING PERSONAL ASSISTANCE SCHEMES

This experience suggested that direct payments are a highly satisfactory way of enabling users to buy in personal assistance. They have been strongly supported by disabled people, by local authorities, by politicians and others.¹⁴ As a result of this widespread support, the Government agreed to introduce legislation permitting direct payments, albeit in a limited form.

Direct payments offer the following advantages:

- supplemented by effective support services, they give maximum control to the individual
- they obviate the need for any administration fee to an intermediary organisation
- they preserve confidentiality by minimising the number of agencies/individuals involved.

The usual practice is for the agreed funding to be paid quarterly or monthly in advance into a separate bank or building society account. The user may choose to pay Independent Living (1993) Fund and any other agreed contributions, such as benefits, into the same account. The basis of the funding agreement and any agreed responsibilities, such as accountability procedures, can be set out in a brief contract.

Direct payments schemes do not mean that users do not require any other form of support. Personal assistance support services offering advocacy, payroll, help in recruitment, etc. are crucial in making such schemes work effectively.

Indirect payments

Third-party payments schemes

Third-party payments schemes are probably the most common way of funding personal assistance at the present time. The authority makes payments to an intermediary body, such as an organisation of disabled people, a council for voluntary service, or an organisation established specifically for that purpose, which then passes the money on to the disabled person to buy in the help needed.

The legal position regarding third-party payments is not entirely clear, as expert opinions are not united. However, it seems unlikely that such arrangements would be the subject of legal challenge.

Third-party payment schemes:

- provide a simple way of giving users control over their own budget
- offer the option for the third party also to provide personal assistance support services
- should be convertible to direct payment schemes if required in the future.



Kingston Independent Living Scheme

Prior to April 1993, direct payments were made by Kingston social services department (SSD) to small numbers of disabled people. A third-party payments scheme was subsequently introduced using Kingston Association of Disabled People (KADP) as a payment intermediary. There is no limit on the age of applicants or the level of payments, and people with learning difficulties can also use the scheme. Assessments are made by the SSD's Independent Living scheme co-ordinator, and users may attend Independent Living skills courses run by KADP.¹⁵

Individual trusts

Using this option the local authority can set up a non-charitable trust as a payment intermediary for the benefit of an individual personal assistance user. An agreed sum of money is paid over to the trust which is managed by the user. The user is a trustee and chooses at least one and preferably three other trustees who can be friends or relatives and may include a person, such as a solicitor, who has particular skills to offer. Money received by an individual in this way is treated as capital and is therefore not subject to income tax. However, bank or building society account interest will incur income tax, which will normally be deducted at source.

Individual trusts offer the following advantages:

- they are very flexible and enable the user to have as much or as little involvement with administrative duties as desired while retaining overall control
- the trustees can provide a helpful source of support.

A potential disadvantage of trusts is the legal requirement that trustees be 'of sufficient mental capacity', which may limit their application with some groups of disabled people.

User-controlled Independent Living schemes (UCILS) in Tower Hamlets

The Living Options Partnership project in Tower Hamlets built on the experience of a disabled person who had pioneered the use of trusts to operate his own personal assistance scheme. The individual was employed as project worker to develop the concept in conjunction with service users and commissioners from the local authority, health authority and FHSA. Working in partnership with senior officers, the project developed the necessary policies and procedures to enable the scheme to become more widely accessible and produced two complementary documents: a step-by-step guide to the processes involved in setting up a UCILS; and a practical guide for people who are considering employing personal assistants for the first time.¹⁶

A conference for disabled people and agencies helped to promote the concept of UCILS, and an Independent Living advocate is being employed to support disabled people in setting up and managing new schemes.



Other arrangements

Using an independent organisation to employ workers on behalf of users

With this arrangement workers are employed by an independent voluntary sector providing agency, such as a local disabled people's organisation. Funding goes directly to the providing agency rather than to the disabled person. The organisation may also be contracted to provide related support services.

Such schemes have the benefit of simplicity from the user's point of view. However, some personal assistance users believe that they cannot exercise the level of control they wish unless they employ workers themselves. Such arrangements therefore are best provided as one of a range of options which can offer greater control if desired.

Merton Association for Independent Access

Merton Association for Independent Access (MAFIA) is a user-led organisation committed to user independence. Under contract from social services, MAFIA employs workers to support clients referred by them. MAFIA helps clients recruit and train workers, pays workers' wages, deals with National Insurance, tax and personal insurance and is responsible for providing emergency cover (via a private agency), if necessary.

The project was developed following consultation between social services officers and two local organisations of disabled people on how to make use of the Independent Living Transfer (ILT). The ILT pays the first £200 of any package and paid for the start-up costs and an annual administration fee. Packages above £200 normally require Independent Living (1993) Fund contributions.

People aged 16–65 with a physical, sensory or learning disability, or who are HIV positive or have AIDS, are eligible if they receive middle or higher rate Disability Living Allowance. A senior care manager holds the budget and approves each funding agreement following assessment. Users are able to choose between the MAFIA scheme, in-house home care services, private agencies or Community Service Volunteers.

Using private agencies which are paid directly by social services

This is a common variation on the above model, except that private care agencies, rather than a voluntary sector provider, are paid directly by social services.


While the use of private care agencies may play an integral role in providing emergency back-up, they are an expensive option if used as the sole source of assistance for people with substantial personal assistance needs. More importantly, many disabled people have found that not paying for the service themselves weakens their position in relation to the service provider, impedes flexibility and reduces their choice and control.

Volunteer schemes

The best known volunteer scheme is Community Service Volunteers (CSV), which places volunteers with disabled people to provide support. Sheltered Housing and Assistance for Disabled People (SHAD) schemes make use of CSV in providing support combined with accommodation.

Volunteer schemes may have a place if they are the deliberate choice of disabled people, although it is difficult to see why disabled people would choose them if offered the alternative of employing personal assistants. Although volunteer schemes are almost certainly cheaper to run, the disabled person usually has far less control over who the workers are. Given that one of the key principles behind personal assistance schemes is the choice and control that users have over who provides the support they need, this is a major and significant drawback. Many disabled people object to volunteer schemes on principle.

➤ **COMMISSIONING BACK-UP AND SUPPORT SERVICES**



Developing personal assistance support services is just as important as finding ways of giving users purchasing power. Managing personal assistants often requires learning new skills and getting used to a new way of living. Personal assistance users want more choice and control. But they also need expert advice, the opportunity to learn from each other and a sense of security should things go wrong. Users may value services such as payroll or help in recruitment, which make running a scheme that bit easier, perhaps with a view to assuming greater control over these activities as time goes by.

In developing personal assistance support services commissioners will wish to consider the following questions:

- What are the key ingredients in setting up a personal assistance support service?
- What services should a personal assistance support service provide?
- Who should provide personal assistance support services?
- What are the key ingredients in operating a successful personal assistance support service?

IMPLEMENTING PERSONAL ASSISTANCE SCHEMES

Key ingredients in setting up a personal assistance support service

Setting up a personal assistance support service requires:

- the full involvement of disabled people at all stages
- commitment to Independent Living principles from local authority councillors, commissioners, hands-on purchasers (e.g. care managers) and providers
- good communication between departments
- social services and health personnel with clearly defined strategic responsibilities to co-ordinate development in partnership with disabled people and with the time, resources and authority to do so
- tendering requirements which value the experience of user-led organisations and which make it possible for them to apply (user control can be made a contractual requirement)
- adequate start-up funding for the providing organisation and a revenue funding agreement which is long enough to allow sensible planning
- co-ordination at senior level where management structures and budgetary responsibility are devolved to local level
- the support and involvement of the housing authority and of housing associations so that allocation policies and practice complement, rather than hinder, the aims of the scheme.

Southampton Centre for Independent Living

Self-operated care schemes (SOCS) in Hampshire pioneered the principle of user-controlled personal assistance schemes in Britain. However, difficulties in finding personal assistants have always been a concern for SOCS users.

Based at the Southampton Centre for Independent Living (SCIL), the Living Options Partnership project supported the development of a register of prospective personal assistants and disabled people wishing to recruit. Joint finance has been secured to continue funding the service at the end of the development phase. An emergency back-up service has also been piloted based at a local respite facility where access to an emergency register of personal assistants is available outside office hours.

What services should personal assistance support services provide?

There is no universal blueprint. Support services must be developed in response to local disabled people's own priorities. However, the options may include the provision of help with the following:

- **assessment** – helping potential personal assistance scheme users understand the options in order to decide whether they wish to use the scheme.
- **costing the package of support** – by working closely with the disabled person and the care manager involved in the assessment.
- **information and training** – in recruitment, administering tax and National Insurance, managing workers, etc.
- **payroll** – handling the payments to workers who remain employed by the user.
- **recruitment** – helping users to locate and interview potential personal assistants.
- **training** – for personal assistants in the skills they need.
- **emergency back-up** – in the event of an unexpected breakdown in support arrangements.
- **mediation** – helping to resolve disputes between the disabled person and the personal assistant.
- **employing workers** – on behalf of users who do not wish to take on this responsibility.
- **bringing personal assistance scheme users together** – to exchange information and ideas and to provide mutual support.

Who should provide personal assistance support services?

Personal assistance support services should be user-led. This has the following merits:

- It draws on the best available experience – that of disabled people themselves.
- It helps to ensure an ongoing commitment to promoting user choice and control.
- It enables advocacy and information services to be independent of the main funding organisation, i.e. social services.
- It helps meet one of the key policy objectives of community care, that of stimulating the development of a wider range of independent sector providers, especially user-led providers.



IMPLEMENTING PERSONAL ASSISTANCE SCHEMES

Personal assistance support services may be located within existing organisations of disabled people. However, some organisations feel that becoming a service provider could compromise their role in campaigning or policy development and prefer such services to be located in a separate but linked organisation such as a Centre for Independent/Integrated Living (CIL).

Independent Living Scheme (Avon)

Independent Living Scheme (Avon) is based in a newly-established CIL. It acts as a payment intermediary and provides support and advice to disabled people willing and able to manage their own personal assistance arrangements. It also provides a payroll service. The scheme is not intended for those who prefer to use private agency workers on a long-term basis, although these may be used for short-term cover. The scheme operates under a service level agreement with the Social Services Department (SSD) which refers clients who express an interest in using the scheme following assessment. There is no upper age limit although, in practice, users tend to be aged under 66 because of the authority's net cost policy which restricts the SSD's contribution to the net cost of relevant residential care provision.

Interim arrangements may be necessary where no suitable user-led organisations exist. However, the development of user-led alternatives should become a priority as part of an overall Independent Living strategy.

Although some activities such as providing advocacy and training are best located in user-led organisations, there may be scope for services such as payroll to be contracted to commercial agencies or a local Council for Voluntary Service, if necessary.

Key ingredients in operating a successful personal assistance support service

- An emphasis should be placed on providing a wide range of options and on peer support.
- Employing disabled people to operate personal assistance support services can provide useful role-models for users. Normal recruitment timetables may need to be extended to enable appropriate candidates to be located.
- Support services should take advantage of personal assistance users' own experience: in supporting each other through informal networks; in helping to direct the management of the service; or in providing training for other users on a formal basis.

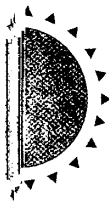
IMPLEMENTING PERSONAL ASSISTANCE SCHEMES

- Personal assistance support services should operate as a resource which is available to facilitate disabled people's independence – not as an agent of control or regulation.
- Temporary secondments from statutory agencies may be useful in helping support services become established and acquire essential skills.
- The collective experience of personal assistance support services should feed back into the planning process and should inform both local and national policy on Independent Living.¹⁷

Users as trainers

Personal assistance users in a number of areas, including Wiltshire and Avon, are employed to provide training for other prospective users.

Greenwich Association of Disabled People operates a Training-the-Trainers service which provides personal assistance users with the skills they need to train other disabled people who wish to set up personal assistance schemes.



SOME KEY ISSUES

Assessment

Personal assistance schemes depend for their success on the development of a truly needs-led assessment process. The role of users in defining their own needs and deciding on the best way these needs can be met is crucial. Assessments which merely focus on functional abilities are not appropriate.

An important consideration is who has responsibility for assessing applicants to the scheme and how assessments are carried out. In most existing schemes, assessments are carried out as part of the normal care management and assessment process with an Independent Living advocate or adviser participating either at referral, during assessment, or in organising the package. However, it is also possible for the assessment itself to be carried out by an independent organisation.

Wiltshire's experience

Access to the Wiltshire Independent Living Fund (WILF) is via assessment by WILF staff or via self-assessment. Eligibility criteria and application and assessment forms were devised by WILF and grants are set by a panel, the majority of whom are users.

IMPLEMENTING PERSONAL ASSISTANCE SCHEMES

The advantage of such arrangements is that needs-led assessments can be carried out more freely and a specific body of expertise can more easily be developed. However, many organisations may not wish to take on the role of 'gatekeeping', which they see as properly belonging to the social services authority. Also, the implications of a legal challenge to the authority regarding an assessment are far from clear.

Eligibility

The principles of equality of access to personal assistance schemes and the need to ration resources may sometimes conflict. Such conflicts are perhaps more likely where personal assistance is funded from a narrow budget rather than being seen as one of a range of options for care management in general. Fortunately, and with the notable exception of the Independent Living (1993) Fund itself, the trend is increasingly for eligibility criteria to be widened to include more age groups and people with a wider range of impairments. Many authorities are also exercising discretion on whether to fund applicants who do not qualify for a contribution from the Independent Living (1993) Fund for packages costing over £200.

Eligibility criteria should aim to include all groups who may benefit from using personal assistance. Where they do not do this, the rationale behind decisions on eligibility criteria should be explicit.

Means-testing

Practice regarding means-testing varies widely. A number of authorities do not means-test personal assistance scheme users, although they may means-test for other services. Given the pressures on resources, policies on means-testing need to be carefully discussed with disabled people so that policy makers understand the full implications of different options. For instance, the impact of means-testing on the broader Independent Living aspirations of disabled people, such as the opportunity to gain employment, should be clearly understood. Requiring disabled people to pay for personal assistance as their income increases merely locks them into a classic poverty trap, with little prospect of escape.

Means-testing applicants to personal assistance schemes undermines equal opportunities principles and creates further obstacles to disabled people becoming financially independent.



Higher-cost packages

Independent Living (1993) Fund grants cannot be accessed for packages of support costing over £500 per week in total. Again, many authorities exercise discretion in funding such packages in their entirety on the basis that they are still likely to be more cost-effective than institutional alternatives and, most importantly, that they are the disabled person's preferred option.

On principle, no disabled person should be consigned to institutional care against their will, regardless of the cost of the package of support in the community.

Training

Personal assistance schemes can easily be undermined if care managers do not subscribe to the principles and practice of Independent Living. User-led training for health and social services staff is increasingly common and is essential if change in professional attitudes is to be achieved and sustained.

Costing personal assistance packages

The way Independent Living packages are cost is crucial in determining how effectively they lead to improvements in quality of life.

In assessing the level of support required, all packages should include help with personal care, domestic needs and engaging in social activities. Assistance with educational and employment activities is more complex because funding may be available from other sources, for example the Access to Work scheme available through the Department of Employment's Placement Advisory and Counselling Teams. However, if funding from these sources is not sufficient, the user should be able to access top-up funding to achieve a comprehensive and integrated package.

Costings should include an element to cover each of the following:

- salaries
- employer's National Insurance contributions
- sickness and holiday pay
- recruitment – advertising and interview expenses
- insurance
- bookkeeping
- auditing
- administration and management.



IMPLEMENTING PERSONAL ASSISTANCE SCHEMES

There is evidence that new personal assistance scheme users consistently underestimate the amount of assistance they need. It is essential that support and advice on assessing needs and costing packages is available to the disabled people at the time of the assessment. Unless packages are cost realistically, users will find it difficult to be good employers, and the security of arrangements will suffer in the long term. Needs and costings should be reviewed periodically and at the request of the user.

Accountability

Statutory agencies have a duty to use public funds wisely and to monitor that they are being spent effectively. Most users understand and accept this. However, fears over the potential for abuse should not lead authorities to over-react by introducing heavy-handed or unnecessarily bureaucratic procedures for monitoring expenditure. The most effective guarantee that resources will be well spent is that the user has been accurately assessed and relies on the support purchased to lead an independent life.

KEY POINTS

- Commissioners should favour models which give users maximum control over their personal assistance budget, together with options to delegate administrative duties to a third party.
- Legislation permitting, direct payments should be the first choice as a method of payment.
- Commissioners should actively promote the development of personal assistance support services which are user-led.
- The more services a personal assistance support service can offer, the more disabled people will be able to use the scheme.
- It is not essential for third-party payments to be made through the same organisation which provides support services.
- Assessments must be truly needs-led.
- User-led training for care managers involved in assessment may be needed.
- Disabled people undergoing assessment should have access to independent advice and advocacy at the time of assessment.
- Personal assistance packages must be adequately costed to allow users to be fair employers and to avoid costly emergencies.



5 Monitoring and evaluating personal assistance schemes

Involving users in monitoring and evaluating a personal assistance scheme is essential for a quality service. Monitoring will need to assess whether standards set out in service specifications are being met, while evaluation will seek to establish whether the broader aims of the service are being achieved.

Information obtained through monitoring and evaluation should, of course, be used to improve the service provided or it is a waste of time.

Commissioners should aim to:

- set standards which are based on the experience of users
- involve users in the process of evaluation.



➤ SETTING STANDARDS WHICH ARE BASED ON THE EXPERIENCE OF USERS

What should be measured when assessing the performance of a personal assistance scheme? Commissioners will wish to assess aspects such as: the cost of the scheme; the numbers of people using it; and how the service is being delivered. Information on who is using the scheme will be important in determining whether all sections of the community have equal access to it.

The most important thing to be measured, however, is how the people using the scheme experience it – what impact does it have on their quality of life?

Setting standards that reflect the quality of service which users require in any scheme, and translating these into meaningful service specifications are critical. Inevitably, agreeing standards will involve a process of negotiation between purchasers, providers and users. However, it is vital that users play a central role in developing standards which are based on their own experience of using the service in order to ensure that appropriate definitions of quality are used.

For instance, a group of personal assistance scheme users could be invited to make a list of the important attributes of a scheme which is working well and another of what happens when things do not work well. Users might identify the following features:

- receiving support and advice during assessment so that they feel they have enough information to make an informed choice

- getting as much help as they need to deal with administration
- receiving enough funding to avoid being left without assistance when it is needed
- receiving payments via a third party on time
- being able to use personal assistants for help with the activities which are important to them (e.g. in meeting childcare responsibilities)
- feeling that their right to confidentiality is being respected by statutory and support service staff
- being able to change the amount of assistance they receive or the way they use the scheme.

These issues could be incorporated into service specifications and also used to design a questionnaire for all users to complete periodically.

➤ INVOLVING USERS IN THE PROCESS OF EVALUATION

Users may be involved more directly in the evaluation of a scheme if they are resourced to do so. User groups can be a valuable way for personal assistance scheme users to provide peer support and can also be a useful focus for evaluating a scheme. Users and user groups can either be commissioned to carry out an evaluation themselves, or to oversee the process when an external consultant is employed.

Avon's experience

In Avon a personal assistance users advisory group has been established at the Centre for Integrated Living (CIL), which provides the local personal assistance support service. The group is a sub-group of the management committee of the CIL, and its purpose is to look at how the support service is run and to consider aspects of policy concerning personal assistance. The advisory group is represented on the CIL's management committee.

👉 KEY POINTS

- Standards must reflect the criteria which users themselves feel are important in making the scheme work.
- Users can be resourced to evaluate whether standards are being met and how improvements could be made.

6 Financing personal assistance schemes

➤ INDIVIDUAL PACKAGES

There are essentially four possible sources of funding:

- **Independent Living (1993) Fund**
- **social services funding**
- **joint funding**
- **personal income and benefits.**

The Independent Living (1993) Fund

The original Independent Living Fund (ILF) was established in 1988 as a result of protests over changes in the social security system at that time. Set up as an independent government-funded charitable trust, ILF was making payments averaging £115 per week to nearly 21,500 people when it came to an end in March 1993.

Two new funds replaced ILF:

- the Independent Living (Extension) Fund, which continues payments to existing ILF recipients
- the Independent Living (1993) Fund (now referred to as the '93 Fund'), which is a much restricted version of the original ILF open to new applicants.

The 93 Fund is able to provide a weekly cash payment to top up provision from other sources. It is intended to complement rather than replace existing statutory responsibilities. Although applications must be made in conjunction with social services departments, grants are made directly to the disabled person. Local authorities are required to make provision up to the value of £200 per week. Applicants must be disabled people aged 16–65 who are in receipt of the higher care component of the Disability Living Allowance.¹⁸

Where users are recipients of the 93 Fund, they should be able to choose whether to receive the local authority's contribution in the form of services or as a cash equivalent.



Because of the tight eligibility criteria and the fact that applicants are also means-tested, many prospective personal assistance users are unable to access help from the Fund. Therefore flexible funding policies are needed to ensure that some people are not unfairly excluded from access to personal assistance.

Social services funding

Some longer-established personal assistance schemes (e.g. Hampshire's SOCS) continue to be funded, at least in part, from mainstream funding set aside for the purpose. However, most new schemes make use of either the Special Transitional Grant (STG) or the Independent Living Transfer (ILT).

The ILT is that element of the STG intended to replace the funding which disabled people would have received from the 'original' Independent Living Fund. Some social services departments have ring-fenced ILT funding to fund personal assistance and personal assistance support schemes for people with physical and sensory impairments.¹⁹

As ILT funding becomes absorbed into mainstream revenue support grants, it is crucial that social services authorities identify and ring-fence at least equivalent sums for the purpose of financing personal assistance packages and support services.

Consideration should also be given to the creative use of budgets not normally associated with personal assistance, such as day centre budgets.

Joint health/social services funding

Personal assistance schemes aim to provide the user with a flexible, seamless support service. Users often find attempts to distinguish between medical and social needs unhelpful and irrelevant. However, where elements of support which have previously been provided by health services can be sensibly incorporated into an integrated package of support, it may be appropriate for the health authority to contribute towards the cost. For example, someone with intensive personal assistance needs moving out of a long-stay hospital could be funded jointly by health and social services.



Peter's story

Peter uses a ventilator to help him breathe. He also needs help with practically all his daily activities, including washing, dressing, bladder and bowel care, eating and drinking, as well as running a household and pursuing a home-study course.

With a combination of health and social services funding Peter employs two full-time and two part-time personal assistants. The local specialist hospital (where Peter lived for several years before setting up the scheme) helps him train the personal assistants in handling the ventilator and coping with his personal care needs.

Although the package is more expensive than most personal assistance schemes, it is still considerably cheaper than the cost of keeping Peter in hospital. Most importantly, it is his preferred choice as it offers him a vastly improved quality of life.

Personal income or benefits

As a group, disabled people remain among the most economically deprived sections of the community. Consequently, few disabled people are even able to contemplate paying for the personal assistance they need from private income. Social security benefits such as the care component of the Disability Living Allowance and the Severe Disability Premium are inadequate to pay for more than a few hours of assistance. Moreover, these benefits are intended to compensate those who qualify to receive them for the numerous extra costs which disabled people incur, of which the cost of personal assistance is only one.

Although 93 Fund support is conditional on users contributing part of their benefit towards the cost of the scheme, when the fund is not involved local authorities should exercise their discretion to ignore these benefits.

Funding personal assistance support services

Many existing support services have been funded using the ILT via service level agreements.²⁰ In most cases, the service is funded in such a way that it is free to the user. An alternative approach would be to include support services costs in the funding for users so that they can choose how this is spent. Although this would, in principle, extend the choice available to users, in practice it may complicate the development of new user-led support services.

Some support services have been funded by grants from trusts but this is becoming more difficult as personal assistance becomes part of mainstream service provision.

KEY POINTS

- Funding for personal assistance schemes and support services needs to be ring-fenced from the ILT or others sources.
- Joint funding with health should be explored where appropriate for both individual personal assistance packages and support services.



7 Conclusion

Health and social services commissioners have exciting opportunities to develop services which can genuinely transform disabled people's lives. To do so they must be prepared to embrace new ideas and new ways of working. They must work *with* users rather than *for* them. They must be prepared to take risks and invest in long-term gains. Above all, they must listen to what disabled people are saying about what they want from personal assistance and be prepared to help them achieve it.

Commissioners face some difficult decisions, not least in resolving tensions between growing expectations and finite resources. Clear policies need to be developed in partnership with users about how resources are allocated and spent. As some of the examples in this document illustrate, creative solutions which meet users' real needs are both possible and achievable.



Notes

1. Morris J. *Community Care or Independent Living*. York: Joseph Rowntree Foundation, 1993, p.7.
2. Crosby N, Jackson R. *The Seven Needs and the Social Model of Disability*. Derbyshire Coalition of Disabled People, 1988.
3. See, for example:
Morris J. *Community Care or Independent Living*. York: Joseph Rowntree Foundation, 1993.
Barnes C. *Making Our Own Choices: Independent Living, personal assistance and disabled people*. Halifax: British Council of Organisations of Disabled People, 1993.
Kestenbaum, A. *Cash for Care: A report on the experience of Independent Living Fund clients*. Nottingham: ILF, 1992.
Zarb G, Nadash P. *Cashing in on Independence: Comparing the costs and benefits of cash and services*. London: Policy Studies Institute/British Council of Organisations of Disabled People, 1994.
4. See: Begum N. *Beyond Samosas and Reggae. Guidelines for developing services for Black disabled people*. London: King's Fund, 1995.
5. Department of Health. *Care Management and Assessment: Summary of practice guidance*. London: HMSO, 1991, 4 (para 11).
6. See 5, p.7.
7. Department of Health. *Community Care in the Next Decade and Beyond: Policy guidance*. London: HMSO, 1990, (para 3.24).
8. See 7, p.25 (para 3.17).
9. Department of Health. *Getting the Message Across: A guide to developing and communicating policies, principles and procedures on assessment*. London: HMSO, 1991, p.6.
10. Department of Health. *The Patient's Charter and You*. London: HMSO, 1995, p.18.
11. See 3.
12. Oliver M, Zarb G. *Greenwich Personal Assistance Schemes: Second year evaluation*. London: Greenwich Association of Disabled People, 1992.
13. Zarb G, Nadash P. *Cashing in on Independence: Comparing the costs and benefits of cash and services*. London: Policy Studies Institute/British Council of Organisations of Disabled People, 1994.
14. See 3.
15. Other areas which operate third party payment schemes include:
Avon; Wiltshire; Norfolk; Nottinghamshire; Lothian; Hampshire; Sheffield; Strathclyde; Birmingham; and Essex.
16. Walsh, B. *User Control and Employing Personal Assistants for Independent Living*. Disability Advocacy Network, 1995.
Walsh, B. *How to Set up Trusts and User Controlled Independent Living Schemes*. Disability Advocacy Network, 1995.
17. A detailed report on setting up personal assistance support services is being prepared by the Disablement Income Group.
18. Further details on the eligibility criteria for applicants, which services the 93 Fund can be used to purchase and which services can be included in the local authority's contribution are available from ILF's headquarters in Nottingham.
19. For a comprehensive account of how ILT is being used by social services departments, see 20 below.
20. Kestenbaum A. *An Opportunity Lost?* Nottingham: ILF, 1995.



Bibliography

Living Options publications

Begum N. *Beyond Samosas and Reggae: Guidelines to developing services for Black disabled people*. London: King's Fund, 1995.

Begum N, Fletcher S. *Improving Disability Services: The way forward for health and social services*. London: King's Fund Centre, Living Options Partnership Paper No. 3, 1995.

Fiedler B. *Getting Results: Unlocking community care in partnership with disabled people*. London: King's Fund Centre, Living Options Partnership Paper No. 1, 1993.

Fiedler B. *Living Options Lottery. Housing and support services for people with severe physical disabilities*. London: The Prince of Wales Advisory Group on Disability, 1988.

Fiedler B. *Tracking Success: Testing services for people with severe physical and sensory disabilities*. London: King's Fund Centre, Living Options In Practice Project Paper No. 2, 1991.

Fiedler B, Twitchen D. *A Framework for Action: Developing services for people with severe physical and sensory disabilities*. London: King's Fund Centre, Living Options In Practice Project Paper No. 1, 1990.

Fiedler B, Twitchen D. *Achieving User Participation: Planning services for people with severe physical and sensory disabilities*. London: King's Fund Centre, Living Options In Practice Paper No. 3, 1992.

Fletcher S. *Evaluating Community Care. A guide to evaluations led by disabled people*. London: King's Fund Centre, 1995.

Morris J. *The Power to Change: Commissioning health and social services with disabled people*. London: King's Fund Centre, Living Options Partnership Paper No 2, 1995.

Publications on Independent Living

Barnes C. *Making Our Own Choices: Independent Living, personal assistance and disabled people*. London: British Council of Organisations of Disabled People, 1993.

Brisenden S. *A Charter for Personal Care*. Disablement Income Group, 1989.

Craig G. *Cash or Care: A question of choice? Cash, community care and user participation*. York: Social Policy Research Unit, University of York, 1992.

Dawson C. *Report on Norfolk Independent Living Project*. Available from Daniel's Publishing, 38 Cambridge Place, Cambridge CB2 1NS, Tel: (01223) 467144. Also summarised in: Joseph Rowntree Foundation *Social Care Research Findings* No 61.

Glendinning C, McLaughlin E. *Paying for Care: Lessons from Europe*. HMSO.

Greater London Association of Disabled People (nd). *Declaring Independence: A guide to Independent Living*. GLAD/LWT.

Greenwich Association of Disabled People. *Guidelines for Self-operated Care Scheme Users*. London: GAD, 1991.

Greenwich Association of Disabled People. *Evaluation of an Independent Living skills training project*. York: Joseph Rowntree Foundation *Social Care Research Findings* No 48.

Greenwich Association of Disabled People. *A User's Guide to Self-operated Care Schemes*. London: GAD, 1993.

Hampshire Centre for Independent Living. *HCIL 91: Promoting the philosophy and practice of Independent Living and empowering disabled people*. (Leaflet).

Hampshire Centre for Independent Living. *HCIL Guide to Independent Living*. HCIL, 1995.

Kestenbaum, A. *Cash for care: A report on the experience of Independent Living Fund clients*. Nottingham: ILF, 1992.

Kestenbaum, A. *Making Community Care a Reality*. Nottingham: ILF, 1993.

BIBLIOGRAPHY

Kestenbaum, A. *An Opportunity Lost? Social services' use of the Independent Living Transfer*. Disablement Income Group, 1995. See also Joseph Rowntree Foundation *Social Care Research Findings* No. 63.

Lahey, J. *Caring about Independence: Disabled people and the Independent Living Fund*. London: Policy Studies Institute, 1994.

Lahey, J. *Paying for Independence*. London: Policy Studies Institute, 1993.

Laurie, L. *Building Our Lives: Report of the Housing and Independent Living Conference*. London: Shelter, 1992.

London Boroughs Disability Resource Team. *Guidelines for Independent Living Schemes*. London: LBDRT, 1990.

Lothian Region Social Work Department. *Independent Living in Lothian: A practice guide*. 1994.

Morris J. *Community Care or Independent Living*. York: Joseph Rowntree Foundation, 1993.

Morris J. *Independent Lives? Community care and disabled people*. Macmillan Press Limited, 1993.

Oldman, C. *Paying for Care: Personal sources of funding care*. York: Joseph Rowntree Foundation.

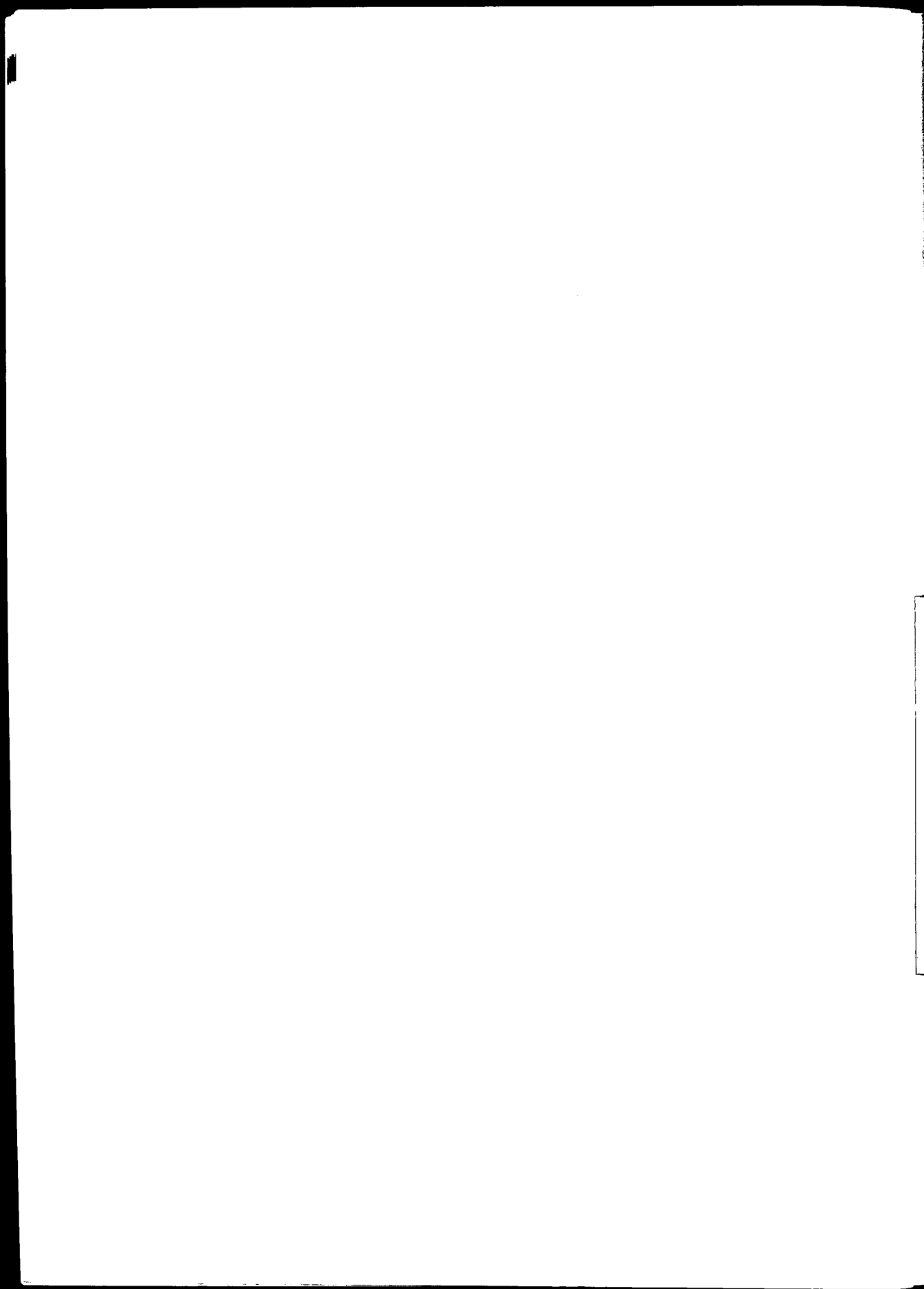
Oliver M, Zarb G. *Personal Assistance Schemes: An evaluation*. London: Greenwich Association of Disabled People, 1993.

Walsh, B. *How to Set up Trusts and User-Controlled Independent Living Schemes*. Disability Advocacy Network, 1995.

Walsh, B. *User Control and Employing Personal Assistants for Independent Living*. Disability Advocacy Network, 1995.

Zarb G, Nadash P. *Cashing in on Independence: Comparing the costs and benefits of cash and services*. London: Policy Studies Institute/British Council of Organisations of Disabled People, 1994.





King's Fund



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More disabled people are opting to run Independent Living schemes which allow them to control their own funds to employ their own personal assistants. This report provides a guide to the different stages of setting up Independent Living schemes with appropriate back-up and support. It includes different models of Independent Living schemes, including trusts, and a strategy for commissioning, financing, costing and evaluating schemes. It offers practical help for commissioners to establish effective purchasing arrangements.

