

Not just the job

Report of a working group on disabled people using personal assistance and work incentives

Marilyn Howard

The Joseph Rowntree Foundation has supported this project as part of its programme of research and development projects, which it hopes will be of value to policy makers, practitioners and service users. The facts presented and views expressed in this report, however, are those of the author and not necessarily those of the Foundation.

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Summary

A working group was set up by the Joseph Rowntree Foundation, the National Centre for Independent Living and the Disability Rights Commission in 2001 to examine the 'personal assistance trap'. This occurred where someone who had support from their local social services department or the Independent Living Fund moved, or wanted to move, into paid employment, only to find that they would have to pay a significant proportion of their earnings towards their support costs.

Personal assistance means the support necessary to enable someone to undertake tasks of everyday living. This support can be delivered through services or payments.

By the end of 2001, guidance to local authorities about charging for community care services, and a review of the Independent Living Funds, recommended that earnings should be disregarded when means testing for support packages. This change represents a considerable achievement for the working group

and for the government departments concerned. The timing and process of the working group was important in influencing and informing members and the policy-making process.

This report is not simply a record of the working group's proceedings. It examines the barriers to work faced by disabled people who need support and, most importantly, identifies some key principles against which the current system and future options can be measured. It also highlights remaining obstacles to employment and anomalies within the current system, which could be addressed in the short to medium term.

Chapter 1 sets out the background to the working group (with further details in Appendix I).

Paying for support packages

Assessing someone's financial contribution is often done through a means test. The Independent Living Fund adopted a means test from Income Support – the main means-tested benefit – and as more councils have begun to charge for services,

largely due to budgetary pressures, many have adopted similar means-tested approaches to charging (Chapter 2).

The impact of support systems on the individual

There are six dimensions of the impact of support systems on the individual:

1 Financial disincentives to work could be created when means tests took account of individual and partner earnings. In disregarding earnings, the government has acknowledged this problem.

2 Uncertainty surrounding the transition to work could be created by the interaction of several complex systems of support and benefits. Working can trigger a review of DLA and disabled people can be confused about benefits and tax credits. Information is not routinely available and individuals could be vulnerable to any mistakes by advisers.

3 A 'postcode lottery' can be created as eligibility and charges for social services can vary by authority area. This could make it difficult for people to move jobs or home as both support systems and Access to Work have to be re-assessed and the same level of support may not be available from the new authority.

4 Complexity of different systems and their interaction. Each system is complex (making it more difficult to establish the impact of working on the support received). Support from one source could affect what another gave. People could have to undergo several means tests. Each system has different monitoring requirements, people having to account to each separately.

5 Personal assistance users may also have feelings of insecurity due to frequent review by the different systems of support. People feared that reviews could lead to support packages being reduced or withdrawn if someone is considered 'too expensive' to keep in the community. Work could also trigger a review and result in a lower level of support.

6 Ethnic minority disabled people, and people with learning difficulties, face additional difficulties in obtaining services (Chapter 3).

Barriers to work faced by personal assistance users

Personal assistance users can encounter additional barriers to employment resulting from the low expectations of others. Working can be seen as evidence that someone is no longer disabled, so risking the reduction or withdrawal of support packages.

As the employment status of personal assistance users is rarely recorded, there is limited information about how many personal assistance users are in work or would like a job. Less than one per cent of Independent Living Fund recipients are working. Estimates suggest that one in five personal assistance users could be working and a further one in five might want work.

People with support needs may be at different points along a spectrum of 'distance from the labour market', and expectations of employment and social care professionals can be a significant factor in whether someone moves nearer to the labour market. Financial disincentives may become more significant when someone is closer to the labour market, perhaps with a specific job in mind. The earnings disregard could help people in the phase of securing work, but at the stages of job search or wanting work, someone with income that can be taken into account could be liable to pay a higher charge than when working.

The disregard of earnings could affect the 'unemployment trap' (when people are little better off in work) by boosting disposable incomes in work and reducing them out of work, if people have income that can be charged against. The 'poverty trap' (where gross earnings are reduced by withdrawal of benefits and increased taxes) would have worsened had

earnings still been taken into account to pay for support (Chapter 4).

The objective of a 'level playing field' and key principles

In the course of examining the problems of personal assistance users and work, the working group felt that the main objective of reform should be to create a 'level playing field' between people who use personal assistance and those who do not. More specifically, the group identified nine principles to inform policy options:

- People with support needs should have the opportunity to work and to progress in work, and without financial penalty.
- Access to funding for services and payments, and charging policy, should be consistent across the country.
- People with support needs should not be financially penalised for living with a partner, nor should the partner face financial disincentives to work.
- Any system of funding a level playing field for personal assistance users should not result in a more limited service (such as, for example, changes to access or eligibility) for other service users.
- Any system providing support should be as simple, accessible and predictable as possible.

- Funding should cover all aspects of support needs; including all that is necessary for disabled people to operate as good employers.
- People receiving personal assistance should be supported to use the money effectively.
- People receiving funding for support should be accountable for what they receive.
- The accountability of funders should be transparent.

The impact of the current system is then assessed in outline against these principles (Chapter 5).

Options for setting a financial contribution

The working group considered a range of options for paying for support packages. *Removing contributions for support at the point of use* was considered to be the option most likely to achieve a level playing field and match up to the principles, although it was recognised that this was unlikely in the short term because of the potential cost. The group then considered alternative options.

Improving means testing was the approach adopted by government, affecting each of the three main elements of the means test (income taken into account, expenses offset and the income considered available to pay for support). The cumulative impact is difficult to predict;

however, financial disincentives to work or to save should be reduced; offsetting disability spending could help people with chargeable income; and the Income Support 'buffer' could protect those on lower incomes. The principles of work and partnerships might be met in part, but other principles may not be met if, as a result, the system became more arbitrary and complex, it was inconsistently applied across the country, or it affected other users' service or charge.

A further option, *setting a contribution without a means test*, would probably entail a minimal charge against disability benefits which are intended to help towards the costs of disability (as done nationally by the Independent Living Fund and a minority of local authorities). While this would be simpler and more consistent across the country, if there were some resource implications, additional funding would be required so as not to penalise other users. If support services are fragmented, a ceiling or integrated charge across all sources of support may be needed (Chapter 6).

Options for integrating support services

The group also considered how consistency in the delivery of support packages at home and at work might be achieved. While assessment and funding for support could be

undertaken more centrally, provision of assistance invariably has to be local (either through local services or direct recruitment of personal assistants by the individual). Options for the longer term include a 'seamless support agency', which could be focused on those of working age, or those receiving direct payments. Mechanisms could include building on 'models' like the Independent Living Fund or expanding Care Trusts. Other shorter-term options include sharing procedures (such as assessment and accountability) between agencies (Chapter 7).

Key themes and timescales

Chapter 8 concludes the discussion by highlighting some key themes, remaining anomalies within support systems as well as other persisting barriers to employment, especially those which can be tackled in the short to medium term. Other medium-term changes in a range of policy areas could add to the complexity facing personal assistance users, but also present opportunities for further change, such as shared procedures between agencies. The future of support services also needs to be integral to potential longer-term developments such as local government funding and regional government.

1 Introduction

Chapter summary

Joseph Rowntree Foundation research identified a ‘personal assistance trap’ whereby people who received cash or support services could find that, if moving into work, they could pay much of their earnings towards their support package because support was means tested.

The number affected by the personal assistance trap remains unclear, although it is likely to be a small proportion of disabled people who have support packages and of disabled people as a whole.

In early 2001, the Joseph Rowntree Foundation, together with the National Centre for Independent Living and the Disability Rights Commission, set up a working group to consider ways of tackling this problem. That same year the Department of Health launched new guidance to local authorities on charging for community care services and the Independent Living Fund’s role in making payments was also reviewed. Both reviews resulted in earnings being disregarded in the calculation of how much someone would be expected to pay for their support. This is a major achievement for the working group and should make real inroads into the personal assistance trap. This report highlights the issues and options considered by the working group, including the principles that the group felt could inform the process of future policy-making in this field.

Historically, disabled people who need assistance with some of the tasks of everyday living have been assumed to need care, not work. Research published by the Joseph Rowntree Foundation in 1997 (*Work, rest and pay: The deal for personal assistance users*) revealed a ‘personal assistance trap’, deterring disabled people from entering or progressing in work (Kestenbaum and Cava 1998). This trap arose because the support provided or paid for (from, for example, local authority social services departments or the Independent Living Fund) was often means tested. As a result, people with earnings could be asked to pay significant amounts towards the costs of their assistance – which could be higher than parents might expect to pay in childcare costs. Paying towards their support packages could often leave people with disposable income not far above Income Support level, which meant there was little incentive to work – even for people earning an average wage of £20,000 a year.

Work, rest and pay considered the example of Michael, a young man with personal assistance needs who had just completed university and was living temporarily with his parents until he was established in work. He needed 35 hours a week support if living with parents (a joint local authority/Independent Living Fund package of just over £274), and live-in care (amounting to £400) if living in his own home. If he worked for wages of £234.49 a week he would be only £30 better off in work, as his net earnings were further taxed at 87 per cent as a result of the means test applied then by the Independent Living Fund.

The existence of the ‘personal assistance trap’ was acknowledged by government in the 1998 Pre-Budget Report, and subsequently by the then Education and Employment select committee of the House of Commons.

Concern about the employment prospects of people who were faced with paying such charges led the Joseph Rowntree Foundation to set up an independent working group of key organisations and individual experts together with departmental officials (as observers). The working group was considered by members to have been educative and effective in informing the policy-making process in a complex field (membership of

the group and its operational brief are contained in Appendix I).

By the end of 2001, guidance to local authorities on charging for community care services, and a review of the Independent Living Funds were published. These addressed the problem of work incentives by disregarding earnings in the calculation of income, and pointed towards closer working between local authorities and the Independent Living Fund. These changes represent a considerable achievement for the working group, although anomalies and other employment barriers remain to be addressed in the short to medium term, and these are explored further in this report.

This report highlights the main issues discussed by the working group, together with some of the principles considered to be important benchmarks against which to measure current and future reforms. The main objective was thought to be the development of a level playing field between those who use assistance and those who do not, so that people with personal assistance needs are not financially penalised. The principles, which follow from that objective, cover both policy and delivery. The report also outlines some ideas for possible future reforms to support and employment systems in the longer term.

Terminology

In this report we refer to ‘personal assistance users’ or people with support needs. This means people who need assistance with day-to-day tasks and activities, which is one element of support for independent living. This often implies ‘human assistance’ which can be delivered through services or cash payments to the individual. We also refer to ‘support packages’ to include either services or cash from whatever source. Although the Independent Living Fund is UK-wide, as local authority provision is now a devolved matter we focus mainly on the systems operating in England, and when considering a wider UK focus this is referred to explicitly in the text.

The report also refers to Disability Living Allowance (DLA). This refers to the care component of that benefit (unless otherwise specified). In relation to assessing a financial contribution, the rules for Attendance Allowance (payable to older people) are similar and so references to DLA should be read as also applying to Attendance Allowance.

How many personal assistance users want work?

There is little information about people who use personal assistants and want to work, although it is likely that they are a minority of the

estimated 6.5 million disabled people of working age. During 2000/01, less than one-third of those receiving local authority services following an assessment were under age 65, mainly comprising 177,000 people with a physical or sensory impairment, 101,000 with a learning difficulty and 113,000 with a mental health problem.¹ People of working age who received direct payments in 2000/01 numbered 3,800 and were mainly people with a physical impairment; an additional 400 payments went to people over 65.²

The Independent Living Fund provides additional support where someone under age 66 has been assessed as needing at least £200 worth of services from their local authority. In September 2001, there were 7,486 clients of the (older) 'Extension' Fund and 8,232 from the newer 1993 Fund (although by the time that the original fund came to an end in 1993, more than 23,000 people had been helped) (Kestenbaum 1996).

Announcements during 2001

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Changes to the way that local authorities and the Independent Living Fund assess financial contributions for support were announced in November 2001. Income from earnings is to be disregarded in any financial assessment, removing a major part of the personal assistance trap.

Main points from Department of Health guidance

- Maintains a council's discretion whether or not to charge.
- Flat rate charges only in limited circumstances.
- Net incomes not to be reduced below Income Support levels plus 25 per cent.
- Individual and partner earnings disregarded.
- Assessment of disability-related spending where DLA is taken into account.
- Capital limits raised to £18,500 with notional income above £11,500.
- Charge assessment should be combined with benefits advice.
- From October 2002 implementation of guidance on Income Support plus 25 per cent, earnings disregard and disability-related spending assessment for people receiving more than 10 hours of home care a week; implementation of the rest from April 2003.

Main points on financial assessment from Independent Living Fund review

- Individual and partner earnings disregarded from April 2002.
- Limit on savings raised to £18,500.

The working group's deliberations have been updated in this report to reflect these changes. The impact of the disregard of earnings, a key issue for the working group, is addressed in the chapters considering barriers to work (Chapter 4) and specific options

(notably Chapters 6 and 7), as well as within the overall system discussed with the principles in Chapter 5.

How the report is structured

Chapter 2 explains the different systems of support (local authorities and the Independent Living Fund) and how they assess any financial contribution towards support packages. Chapter 3 considers the impact of the systems providing for support at home and at work from the perspective of the individual personal assistance user who wants to work. Chapter 4 then goes on to explore the barriers to employment faced by personal assistance users at different stages of 'distance' from the labour market, often as a result of the implicit assumptions within support systems or the way they are organised.

Chapter 5 describes the objective of a 'level playing field' and nine principles identified by the working group which would need to be met for the level playing field to be achieved. The existing system as a whole is then compared with the principles. In Chapter 6 we examine some options for contributing to support packages, ranging from making personal assistance free at the point of use (and so funded in advance or collectively), improving means tests, and setting a contribution without undertaking another means test. Chapter 7 considers different levels and options

for delivery. While assessment and funding could be carried out more centrally, assistance needs to be responsive to the individual, which indicates locally-based provision (either services or through the person recruiting their own assistance). Longer-term options might include various models for a single agency providing support, building on existing structures such as the Independent Living Fund, and Care Trusts. Chapter 8 summarises some of the main themes, the remaining anomalies and barriers to employment, as well as highlighting some further scope for reform in the medium term (such as changes to local government funding and regional structures).

2 Paying for support packages

Chapter summary

The two main systems of providing support – the Independent Living Fund and local authority social services departments – both have a history of expecting users to make some contribution for the services or cash they receive. Historically the Independent Living Fund financial assessment was modelled on the basic means-tested safety net, Income Support. For most of its existence it has taken into account the care component of DLA (or its equivalent), currently assuming half of this as a contribution, and all of the Severe Disability Premium (less any charge made by the local authority). Local authorities have the discretion about whether or not to charge, though more have done so in recent years as a result of budgetary pressures, and many have also introduced tighter eligibility criteria for their services. The Department of Health has stated that the objective of charging is to improve services.

Unlike health care, which is generally free to those who need it at the point of delivery, most people who need support with the tasks of daily living are expected to pay a contribution towards the support they receive. There are two main sources of cash or services for support: local authorities (through their social services departments) or the Independent Living Funds, providing a cash top-up for people who receive at least £200 worth of services or direct payments from their local council.

In this chapter we consider the context within which these systems expect a contribution from individuals and the ways in which they decide who should pay and the amount of their contribution.

Why the Independent Living Fund charges

The Independent Living Fund was set up in 1988 when Supplementary Benefit was replaced by Income Support. It operates as an

independent trust, accountable to a Board of Trustees, funded by the Department for Work and Pensions. The original Fund (now called the Extension Fund) was open to direct applications from individuals, but was closed in anticipation of the implementation of community care legislation by local authorities. A new fund was set up in 1993 with referral from local authorities once someone was assessed as needing services costing the local authority between £200 and £500 a week (the latter figure was raised to £625 from January 2000).

Having grown out of a means-tested safety net benefit, many of the assumptions within the Income Support scheme governed the Fund's financial assessment, for instance, the level of savings and earnings taken into account (see Chapter 6). The review of the Independent Living Fund considered that there were no longer reasons to justify identical eligibility criteria with Income Support, as it provides for basic living costs while the Independent Living Fund provides cash support for care costs additional to everyday living costs for a discrete group of people who have expenses beyond the general population because of their disability (Department for Work and Pensions 2001).

In practice the Independent Living Fund expects all clients to pay at least half of their DLA care component, although the purpose of DLA is for

general disability-related costs (discussed further in Chapter 6). Similarly anyone whose Income Support includes the Severe Disability Premium is expected to contribute all of this towards their care. For those above Income Support level who undergo a financial assessment, rules about how much earnings to take into account were gradually eased (see Chapter 3).

Not surprisingly most Independent Living Fund clients receive Income Support, as those on higher incomes would be excluded from payments as the means test began to bite. In September 2001, 87 per cent of Extension Fund clients and 79 per cent of 1993 fund clients received Income Support (Department for Work and Pensions 2001). Changes to the means test announced in the review (such as the disregard of earnings) could result in more people with incomes above that level being supported by the Fund.

Why local authorities charge for support services

Local authorities have discretion whether or not to charge, however, if they do so it must be reasonable and councils must have regard to whether it is practicable for someone to pay.³ Department of Health guidance states that the objective of charging is to improve the services provided (see Chapter 6).⁴ Since 1997 local authorities may make a cash payment

in lieu of a service, initially available only to those aged 18–65, but from 2000 eligibility was extended to those aged over 65 and from 2001 to young people aged 16–17. Recipients of these ‘direct payments’ have to be charged in the same way as if the service had been provided.

Research carried out during the mid-1990s highlighted that many local authorities were revising their charging policies, often making them more complex, balancing the need to get more income from charges against protecting the poorest and achieving fairness across groups (Kestenbaum 1997). Financial pressure was the most important factor driving this, as local authorities looked to charges to ease pressure on budgets and minimise service cuts (Baldwin and Lunt 1996). By 2000, only 6 per cent of councils were not charging for services (except for meals), the rest having four types of charging policies:

- Flat rate: 10 per cent charge most users the same.
- Use only: 19 per cent charge a variable amount based on intensity of use.
- Means tested but not related to use: 10 per cent charge on user’s means only.
- Means and use: 55 per cent charge on both the user’s means and the amount of services they receive (Audit Commission 2000).

Local authorities receive a central government grant for social services (the Standard Spending Assessment, based on a set formula); any amount required over that level has to be raised through increasing council tax. Within this formula, central government assumed that councils recover about 9 per cent of their spending from charging individual users, which was used by some local authorities to justify new or higher charges (Audit Commission 2000).

Social services underfunding

There has been a growing gap between grants for social services departments and the budgets set by councils locally (10 per cent in the last three years). As a result, three-quarters of departments in one survey had overspent in 2000/01.⁵ The continued spending pattern is 2 per cent over the original budgets set by local authorities (about £200 million) on top of the already growing gap between the government’s funding formula for social services departments and local budgets.

This pressure on budgets means that many local authorities have revised their charging policy, often within their annual budgeting process, resulting in some users having regular increases in the amount they are expected to pay. In one local authority, the charge increased from £30 to £100 a week over three years. (One of the advantages of the Torbay system, discussed in Chapter 6, was

that charging reviews took place outside of the annual budget round) (Audit Commission 2000).

Budget cuts could also mean people losing Independent Living Fund awards if the costed local authority contribution falls below £200 a week (Kestenbaum 1999).

These pressures have led some authorities to tighten their eligibility criteria, so that some services considered to be lower priority are no longer provided (like domestic assistance) and people with a lower level of need for services like home care, are less likely to receive any service.

Both rationing mechanisms – charging and eligibility criteria – could have a cumulative impact over time. Having more intensive service users who do not have the ability to pay could significantly reduce a local authority's income from charges, leading to pressure to revise the charging system, and so on.

Charge income can raise a significant amount – in one local authority, charging 11,700 people raised over £3 million, equivalent to one-fifth of their home care service budget or 220 full-time equivalent staff.⁶ On average, councils recovered 12 per cent of the costs of a service, however, administering charging could cost one-fifth of the income raised (Audit Commission 2000).

Most users are older people

The majority of users of community care services are older people; in 2000, 72 per cent of those receiving services following an assessment were over age 65. Not surprisingly, most of the people paying a charge are over age 65 (90 per cent in one council).⁷ As a result, in England, charges for services or payments to people living in the community recouped 14 per cent of spending on elderly home care but 7 per cent or less from services to working age adults.⁸

Hence services for older people can dominate those of younger disabled adults.⁹ Similarly the debate about charging has tended to be influenced by concerns about older people. The working group's focus was specifically on people of working age; this is important to bear in mind when we consider principles and options for change (Chapters 5 and 6).

3 The impact of support systems on the individual

Chapter summary

There are six dimensions of the impact of support systems on the individual:

- 1 Financial disincentives to work** could be created when means tests took account of individual and partner earnings. In disregarding earnings, the government has acknowledged this problem.
- 2 Uncertainty surrounding the transition to work** could be created by the interaction of several complex systems of support and benefits. Working can trigger a review of DLA and disabled people can be confused about benefits and tax credits. Information is not routinely available and individuals could be vulnerable to any mistakes by advisers.
- 3 A 'postcode lottery'** can be created as eligibility and charges for social services can vary by authority area. This could make it difficult for people to move jobs or home as both support systems and Access to Work have to be re-assessed and the same level of support may not be available from the new authority.
- 4 Complexity of different systems and their interaction.** Each system is complex (making it more difficult to establish the impact of working on the support received). Support from one source could affect what another gave. People could have to undergo several means tests. Each system has different monitoring requirements, people having to account to each separately.
- 5 Personal assistance users may also have feelings of insecurity due to frequent review** by the different systems of support. People feared that reviews could lead to support packages being reduced or withdrawn if someone is considered 'too expensive' to keep in the community. Work could also trigger a review and result in a lower level of support.
- 6 Ethnic minority disabled people, and people with learning difficulties,** face additional difficulties in obtaining services.

The last chapter showed why and how providers expect individuals to pay a contribution for the support they receive. In this chapter we examine the impact on the individual of receiving and paying for support. Financial disincentives to work will change from 2002 when the revised guidance to local authorities and the Independent Living Fund financial assessment are implemented. Other issues (such as complexity and fragmentation of support systems) will remain. This chapter covers six main dimensions of the impact on the individual:

- 1 Financial disincentives to work.
- 2 Uncertainty in the transition into work.
- 3 A 'postcode lottery'.
- 4 The complexity of different systems and their interaction.
- 5 Feelings of insecurity due to frequent review by different systems.
- 6 Difficulties for some groups in gaining access to support.

Financial disincentives to work

As noted in Chapter 2, if earnings are included as income from which someone can pay for their support, there can be little incentive to work or earn more. During 2001 the Independent Living Fund ignored the first £30 of earnings, took into account 55 per cent of earnings between £30 and £170 and pound for pound on earnings over £200 a week. As a result, however much someone

earned, the maximum 'disregard' of earnings would be £106.50 a week, creating disincentives to promotion or a better paid job. Local authority rules differed but at that time the Department of Health proposal was for a 55 per cent clawback ('taper') on all earnings.

The working group was told about people who had not taken a job which had been offered; who were considering giving up work; or who were working fewer hours simply as a result of the means test on earnings. Disincentives to work also applied to a partner whose income could be included in financial assessments. Both the support and the contributions could depend on a partner:

"For my husband to work I need full-time help at home, but, if he's working we don't qualify for Independent Living Fund because of our income and if he's not working we don't need the Independent Living Fund because he can assist me on a full-time basis ... We manage by my mother (aged 65) and her sisters (aged 67 and 70) coming in on different days of the week." (Maynard Campbell and Maynard Lupton 2000)

As a result, the means test could be a barrier to forming or maintaining relationships. Anecdotal information suggested that, in some cases, relationships were under strain (including domestic violence or break

down) because of the expectation that people should contribute towards their partner's support package. In some cases a partner had not paid the expected contribution, leaving the disabled person in financial hardship or had given up work.

Some people were also means tested several times. Earnings were also taken into account for in-work support such as Housing Benefit or Council Tax Benefit. Housing Benefit is reduced by 65 pence in the £ once someone receives income above Income Support level, and likewise entitlement to the Disabled Person's Tax Credit is reduced by 55 pence in the £ once earnings are above the threshold. In one case an offer of work for £140 a week would have meant one individual paying £46 towards her support package and £27 towards her rent – as the Housing Benefit rules do not offset any contribution for support as an 'allowable expense', she would have been left with a disposable income of £69 a week – £36 less than if she stayed on benefit.

The government has accepted that such means tests create disincentives for the individual and their partner to work, and so the disregard of earnings should remove a large part of this problem. However, some of the other issues facing individuals receiving support are likely to remain, and are discussed in the rest of this chapter.

Uncertainty surrounding the transition to work

Even with the disregard of earnings, uncertainty could remain a significant barrier for many personal assistance users. Leaving the security of benefit income for the uncertainty of in-work incomes, managing financially during the transition into a job, and the need to reclaim benefits, can all affect the decision about whether or not to work (Gardiner 1997). For disabled people the risks may be greater, as demonstrating ability to work can risk losing benefits. DLA is payable whether in or out of work, but working can trigger a review as it may be assumed that the person no longer needs the same level of care or supervision. Disabled people tend to be confused about benefits and tax credits, and frightened of losing benefits altogether, adding to the uncertainty and risk of the transition off benefits into work (Corden and Sainsbury 2001).

If the job does not work out there are rules to help people reclaim benefit at the same rate (the 'linking rule'), reducing risks and anxieties. However, its incentive effect can be limited by lack of information, strict notification procedures and medical certification on reapplication (Corden and Sainsbury 2001). Being turned down can become a disincentive to work again.

Information about tax credits and in-work help could be important when people are considering work. Although welfare rights staff might be available to help people claim DLA as part of their local authority's approach to charging (see Chapters 2 and 6), there seems to be little routine advice available from social work staff about the implications of returning to work, with few knowing about the Disabled Person's Tax Credit (Griffiths 2001).

New Deal Personal Advisers did not always understand the system and were sometimes reluctant to give specific advice, including 'better off' calculations and tax credits, until the client had a job in mind (Arthur et al. 1999). Both advisers and individuals might have inaccurate or out of date information, so people could be vulnerable to any mistakes by Personal Advisers, the scope for misunderstandings and confusion being greater when dealing with several complex systems.

People can sometimes encounter problems in getting help quickly enough from the Access to Work scheme (see box). Added to uncertainty about benefits and tax credits, problems with Access to Work and personal assistance can be an additional layer of complexity which can undermine the transition into work in the vital first few weeks when someone is getting used to a new job and new routines. In effect, the individual bears the risk.

Key points about Access to Work

Access to Work is a former Employment Service scheme to help disabled people with equipment, fares and support workers to help them in a job. Support is normally granted for three years and support workers can be funded where their practical contribution towards the job itself is assessed as being no more than 20 per cent. During 1999/2000, 20,729 people were helped, of whom about one-fifth (4,133) had a support worker (accounting for 23 per cent of spending) and 5,392 fares to work (26 per cent of spending). The type of help given by a support worker could include general personal assistance at work, such as manual help, fetching and carrying, dressing and toiletry assistance, or generally keeping an eye on the individual. People may get more than one form of help.

The 'postcode lottery'

As noted in Chapter 2, who is eligible for services and how much they have to pay can vary by local authority area (there are 150 councils with social services responsibilities), and elements of discretion remain even with Department of Health guidance on charging. As a result individuals requiring support can be treated differently depending on where they live.

Although the Independent Living Fund operates a UK-wide standard for care and financial assessments, in practice the number of clients varies from 1.5 to 80.0 per 100,000 population (Department for Work and Pensions 2001). Eligibility for the Independent Living Fund is based on referrals from local authorities, and is subject to the awareness of social services staff as well as how authorities cost their services in order to reach the minimum and maximum Independent Living Fund thresholds (£200 and £500 respectively).

As a result, people may encounter difficulties transferring their packages of support if they move jobs or home, which may result in assistance being delayed or the second local authority not funding the same level and type of assistance as the first (Kestenbaum and Cava 1998). Being near work could be particularly important for people with support needs, so that travel is not consuming additional time, effort or finance.

People with Access to Work support may also need to reapply and be reassessed if they move home or job (see also below) (Maynard Campbell and Maynard Lupton 2000).

The complexity of different systems and their interaction

As well as the Independent Living Fund and local authorities, support might be obtained from Access to Work (if someone is in employment) or perhaps also the health authority. These different systems can interact, not always in ways that are helpful to the individual. Complexity within each system can also make it more difficult for individuals to establish the impact of working on the level of support they receive, taking into account both financial gains and losses and the energy required to maintain their support.

The amount of support received from one source can be affected by another. For example, someone receiving a direct payment from their local authority can find it is reduced if they also have Access to Work support for their job.

The means test has affected which support system is involved

The different approaches to collecting a financial contribution have resulted in some people withdrawing from Independent Living Fund funding in favour of local authority or health support. Some local authorities felt they funded people who were deterred by the 2001 Independent Living Fund financial assessment, the local authority having statutory responsibilities. In one case a man with a working partner had a weekly

support package worth £770, £400 being paid by the local authority (for which he was charged £17.60). The Independent Living Fund offered £227 per week (net of the partner's contribution). The couple had considered living apart because of the financial pressures. Had they done so the local authority would have been responsible for funding the whole of the package, the cost of which would have increased, as there would have been no live-in carer once his partner left, and the Independent Living Fund could not have contributed anything, the cost being above their limit on any joint package (£625). The disregard of earnings and higher savings limit should reduce the likelihood of this happening in the future.

The Audit Commission has commented on the incentives to 'cost shunting' between social services departments and the NHS, prompting some of the initiatives bringing the two together (see also Chapter 7) (Audit Commission 2000). The definition of 'health' has changed over time, often leading to more provision being picked up by social services, with some assistance bought by local authority direct payments replacing conventional NHS services no longer available, such as physiotherapy (Glendinning et al. 2000). However, this can work in the opposite direction; someone whose Independent Living Fund payment was withdrawn as a result of savings being over the (then) limit

subsequently received some (non-means-tested) health funded services.

Disabled parents might prefer to be supported through adult rather than child services, for fear that the latter might make assumptions about parenting ability, possibly removing the child (Gooding 2000). However, adult support can be charged for (while children's services are not).

People could have to undergo two means tests for support

At least two agencies could be doing a means test on the same person if, for example, that person receives both Independent Living Fund and local authority support; a situation which could become more widespread if authorities follow Department of Health guidance on charging (see also Chapters 6 and 7). Access to Work support is not means tested.

People have to account to each system separately

Each source of support has its own requirement for monitoring and verification of payments, requiring an individual to spend time and effort being accountable to several systems:

"I am running even more administration systems (for Access to Work, Independent Living Fund, Social Services, etc.) all with different rules and regulations!! Aren't our lives complicated enough without the very services who are supposed to

support us making them even more complicated than they were already."

(Maynard Campbell and Maynard Lupton 2000)

Someone receiving Access to Work support normally has to claim reimbursement. For fares to work this entails completing a form every four weeks, which includes their employer confirming that the individual worked on that day, and producing receipts. Verification of how someone has spent a direct payment from their local authority can be via quarterly or six-monthly returns. Dealing with the different monitoring systems can be stressful and time-consuming for individuals to manage, especially on top of work.

In situations where people are given cash payments to employ their own support workers, Personal Assistance Support schemes can help people in their role as an employer. However, such schemes are not uniformly available across the country.

Feelings of insecurity due to frequent review by different systems

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Each of the systems providing support also require proof of continuing entitlement. While public money has to be accounted for, the cumulative impact of being reviewed by several agencies can generate considerable insecurity for the individual.

Local authorities regularly review their social services eligibility criteria in general (often as a result of budget pressures) as well as instigating regular reviews of individuals receiving support. For example, one local authority carried out reviews every six months, more often if circumstances changed. Annual reviews are now recommended.¹⁰

Independent Living Fund clients are now subject to an annual review which includes checking that the person is still entitled to DLA and local authorities are asked to keep the Independent Living Funds informed of any changes in their part of the package. The Independent Living Fund can also change an award at the individual's instigation at any time (Department for Work and Pensions 2001).

Someone receiving Access to Work support could also be reviewed. Authorisation has to be based on an assessment at the time of the claim and reviewed after three years, if not before. So when circumstances change (such as a new job) a fresh claim must be made so it can be assessed at that time, under those conditions.

Many personal assistance users feared that regular reviews could lead to the reduction or withdrawal of support packages from one or more sources. In particular people with high support needs (such as night needs, or living in rural areas), feared they

could be considered 'too expensive to keep in the community' if reviewed after a change in eligibility or cost criteria. Insecurity was reinforced where people had already experienced a reduction (in one case support had previously been cut by £50 a week). Starting work could be considered as a change in circumstances, triggering a review and creating further disincentives for people not wishing to risk the withdrawal or reduction of their support package. A review of charging policy by the local authority could also reinforce uncertainty about support and the ability to pay towards it.

Difficulties for some groups in gaining access to support

People from ethnic minority communities and people with learning difficulties may not obtain the support they need.

While working-age adults from ethnic minority communities are more likely than the white population to have impairments,¹¹ research has also indicated that:

- In the early days of the Independent Living Fund, minority ethnic recipients were less likely than white recipients to say that they had all the help they needed (Lakey 1994).
- There is also some evidence to suggest that black people have lacked the support to use direct payments and have encountered

difficulty recruiting personal assistants (Butt et al. 2000).

Anecdotal evidence from organisations representing disabled people from ethnic minority communities suggests that, in some areas, they could be asked for additional evidence before a service is considered (thus leading to delays) or have to go through to review stages rather than having their needs met on initial application. Service providers may also hold different expectations about family support that someone from minority ethnic communities might receive. Because of the younger age structure, some disabled people from ethnic minority communities are also disabled parents (including lone parents). As a result of poor services, direct payments could be more effective in promoting independence for people from minority ethnic communities.

People with learning difficulties can be particularly affected by local authorities tightening their eligibility for services as some councils have excluded conditions such as Asperger's syndrome. Direct payments may be more flexible than services, but take-up by people with learning difficulties is low, perhaps as a result of the assumption that they could not manage this kind of support. In 2000/01, fewer than 5 per cent of people receiving a direct payment had a learning difficulty.¹² Promoting direct payments is a key element for the future.¹³ Good quality

services should also ensure that people with complex needs are appropriately supported – including those with additional impairments or autistic spectrum disorder.

The ‘personal assistance trap’ for people with learning difficulties differed from that affecting other people with support needs. This may stem from the particularly negative assumptions on the part of support and employment services about the capability of people with learning difficulties, and the limited gains from working relative to out-of-work benefits if the rate of pay is low (see Chapter 4). Many people with learning difficulties are receiving Income Support, and any earnings above the disregard (now £20 a week) reduces their benefit pound for pound. People living with parents or other family members may find that their family’s reliance on disability benefits adds to the disincentive to work as the potential loss of the person’s benefits might also have a knock-on effect on family budgets.

Although residential care was beyond the remit of the working group, the disincentives to work and independence could be greater for people with learning difficulties living in those settings. For instance, they could earn little more than the basic Income Support disregard before their income is reduced, and the residential charging regime kicks in. In one case someone living in residential care found a job, but the

home took all his money (DLA and earnings) as a charge and so he only had the personal expenses allowance (£16 a week). While there is some discretion for local authorities to increase the personal expenses allowance to encourage independence for young people going to work this seems to be little used (O’Byrne et al. 2000a).

4 Barriers to work faced by personal assistance users

Chapter summary

Personal assistance users can encounter additional barriers to employment resulting from the low expectations of others that they will work. Working can be seen as evidence that someone is no longer disabled, so risking the reduction or withdrawal of support packages.

As the employment status of personal assistance users is rarely recorded, there is limited information about how many personal assistance users are in work or would like a job. Less than one per cent of Independent Living Fund recipients are working. Estimates suggest that one in five personal assistance users could be working and a further one in five might want work.

People with support needs may be at different points along a spectrum of 'distance from the labour market', and expectations of employment and social care professionals can be a significant factor in whether someone moves nearer to the labour market. Financial disincentives may become more significant when someone is closer to the labour market, perhaps with a specific job in mind. The earnings disregard could help people in the phase of securing work but, at the stages of job search or wanting work, someone with income that can be taken into account could be liable to pay a higher charge than when working.

The disregard of earnings could affect the 'unemployment trap' (when people are little better off in work) by boosting disposable incomes in work and reducing them out of work, if people have income that can be charged against. The 'poverty trap' (where gross earnings are reduced by withdrawal of benefits and increased taxes) would have worsened had earnings still been taken into account to pay for support.

The working group's prime concern was people being deterred from working, or considering giving up a job, because they would have to pay a new or increased charge for their support. In this chapter we consider the range of barriers faced by personal assistance users at different stages of distance from the labour market. Even with the disregard of earnings, some financial disincentives remain, in addition to other barriers faced by personal assistance users (created by the negative assumptions underpinning support services and the way they are organised).

Disability disadvantage

Disabled people are less than half as likely to be in work as non-disabled people (Burchardt 2000). In 2001, 47 per cent of disabled people were in work, but those with the lowest employment rates were people with a mental illness (19 per cent) or learning difficulty (24 per cent).¹⁴ Many obstacles to employment – such as employer prejudice and disincentives built into the benefits system – are faced by disabled people regardless of their impairment or illness. Individual impairments and social factors can interact to create a unique set of circumstances for each individual (Hills et al. 2001). The employment rate of disabled people can be linked to the economic cycle and the local labour market; where there are large numbers of non-disabled people in work, disabled

people are also more likely to be employed (Burchardt 2000).

Negative assumptions and delivery of support

Disabled people who use personal assistance encounter another set of barriers to work, stemming from negative assumptions about their ability to work influencing support and employment systems, and in the way in which support is arranged.

Support systems have been governed more by the shift in emphasis from residential to community care rather than employment potential. A common assumption from support services is that disabled people do not work. At a crucial time in planning the transition from school to adult life, few of the professionals involved appear to have any expectation that young people could work (O'Bryan et al. 2000b).

The capacity to hold down a job can sometimes be seen as demonstration that people are not, or are no longer, severely disabled (O'Bryan et al. 2000a). As a result, individuals can risk losing their support package. One personal assistance user stated that as soon as he started work his local authority reviewed his support package on the basis that he must have obtained his support package dishonestly (by over-stating his needs) if he could now work.

A Social Services Inspectorate review of welfare to work for disabled people found that employment for disabled people was not seen as a core activity or priority as the expectation was that disabled people received care, not work (Griffiths, 2001). This was associated with eligibility for services, the main focus being people with 'high-dependency needs' who were not perceived to be seeking work, and the limited capacity for staff to engage in proactive developments.

The way that some support services are organised can also be a barrier to work, for instance, services may not be available to get someone up in time to get to work. In contrast, direct payments can be more flexible by enabling users to organise how and when they receive support, but were either not promoted or take up was low (Griffiths 2001).

Similarly employment systems could hold low expectations of the work potential of some disabled people, particularly those with learning difficulties.¹⁵ The working group heard that the Employment Service did not always demonstrate an understanding of learning difficulties (e.g. people may be sent on a series of courses rather than work placement). Someone with Asperger's syndrome had no support when signing on, and was signposted to jobs which were labelled for someone with a 'learning disability' rather than posts which were appropriate for him as an individual.

Some New Deal Personal Advisers dealing with people with unmet or continuing health/social care needs did not necessarily see impairment as a barrier but felt that extensive personal assistance needs meant that employment was not an option (Arthur et al. 1999). Depending on individual circumstances this may or may not be an accurate perception.

As people receiving benefits increasingly consider employment, there is a pressing need to ensure that they receive adequate and appropriate support and advice on the consequences of working.

Personal assistance users in work

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Perhaps as a result of the assumption that personal assistance users will never work, local authorities do not routinely record the employment status of those receiving their services. A 1997 survey revealed that 59 out of 80 authorities responding funded fewer than five working personal assistance users (Kestenbaum and Cava 1998). The Social Services Inspectorate welfare to work inspection included some councils where work and work aspirations were recorded. In two of the local authority reports 3 per cent and 6 per cent of users were reported to be in work. Of 308 assessments in one authority, 68 per cent were not considered for work, but only in 16 per cent of cases was this because the disabled person did not want to be considered for work.

In May 2001, of around 15,000 Independent Living Fund recipients, 80 were in work (equivalent to an employment rate of less than 1 per cent – see tables A1 and A2, Appendix II);¹⁶ 43 were male, and eight had children; 32 local authorities had at least one 1993 Fund client in work in their area, and 31 had at least one Extension Fund client working; 72 working Independent Living Fund clients lived in England, 15 in London; most were aged between 26 and 45 (see Appendix II). The proposed disregard of the earnings of clients and their partners could affect about 500 people.¹⁷

Estimates from the Centre for Analysis of Social Exclusion for the working group suggested that 18 per cent of personal assistance users could be in work, about half the employment rate of disabled people as a whole (see table A4, Appendix II). Looking specifically at people under age 65 there is some variation by frequency of service use, although as numbers are small they should be seen as estimates rather than definitive figures (Table 1).

A short survey of Personal Assistance Support Schemes carried out for the working group found that, of 46 responses concerning 2,056 users, just

Table 1 Employment status of personal assistance users under age 65 by service use (000s)

	Employed	Not employed	Retired*
Less than once a week	8 (14%)	26 (10%)	5 (19%)
Once a week	26 (44%)	71 (26%)	7 (24%)
2 to 3 times a week	17 (29%)	99 (37%)	9 (34%)
Daily	8 (13%)	73 (27%)	6 (22%)
Total	58	268	28

Source: Estimates from the Centre for Analysis of Social Exclusion based on the 1996/7 Disability Follow-Up to the Family Resources Survey for the working group.

Notes: * sample size small. These figures should be treated cautiously as the base is small and numbers categorised as personal assistance users include those with less intense service use than the group of personal assistance users within the remit of the working group.

over 6 per cent were in work and almost 12 per cent had partners in work. These figures need to be viewed with caution because, as with local authorities, information about work status of users was not routinely kept (some schemes asked users or made estimates). However, 6 per cent is consistent with some of the authorities reviewed by the Social Services Inspectorate – but lower than the Centre for Analysis of Social Exclusion estimates.

Personal assistance users wanting work

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According to the Labour Force Survey, one-third of economically inactive disabled people wanted a job.¹⁸

Personal assistance users are not separately identified in the Labour Force Survey, but estimates for the working group suggested that 19 per cent of personal assistance users wanted work (see Appendix II). Impressions from people working in support schemes were also that around 18 per cent of those not working wanted work.

Assuming that almost one in five personal assistance users might want work it was not clear from any data source the extent to which the *financial disincentive* to work created by charging against earnings had contributed to their being out of work. For instance, there was no indication that personal assistance

users were more likely to work in areas where the local authority did not charge. However, charging was identified by the Social Services Inspectorate as a major disincentive to employment (Griffiths 2001). This was supported by anecdotal evidence from support schemes, suggesting that three-quarters of personal assistance users might have been put off working by charging against earnings.¹⁹

Research has indicated that educational qualifications can increase the chances of work by 30 per cent (men) and 48 per cent (women) (Burchardt 2000). A further analysis by the Centre for Analysis of Social Exclusion (table A4, Appendix II) indicated that a higher proportion of personal assistance users who were working or looking for work had qualifications compared with disabled people who did not use assistance, and so theoretically had a better chance of getting a job.

Clearly the disregard of earnings will tackle a major part of the financial disincentives, however, the extent to which it enables more personal assistance users to move into work will also depend on how much the other barriers are addressed and employment is promoted by support services and advisers. These barriers to employment may also vary according to how close someone is to working.

Distance from labour market

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A review of welfare to work schemes identified different 'stages' of moving back to work, from being 'economically inactive', to 'desire for a job', followed by 'job search' and finally 'securing employment'; each stage influenced by individual and structural factors (Gardiner 1997). At the stage of 'desire to work', barriers included failures in information (about impact of working on benefits); and uncertainty at the stage of 'securing employment'. The New Deal for Disabled People evaluation indicated that concerns about being financially better off in work tended to surface once someone moved nearer to the labour market (Loumidis et al. 2001). This suggests that personal assistance users wanting or looking for work could be particularly affected by financial considerations.

The barriers to work outlined above may affect personal assistance users differently at each stage of distance from the labour market. For instance, furthest away from the labour market ('economically inactive'), *generalised assumptions and low expectations* (on the part of others) might be major barriers. Perhaps it is only at the stage of 'job search' or 'securing employment', when there is a specific job in mind, that the extent of any *financial disincentives* may be revealed. At all stages personal assistance users are likely to be

influenced by the attitudes, assumptions, advice and encouragement of others.

Figure 1 develops the concept of 'distance from the labour market' to highlight potential barriers to work for personal assistance users stemming from support and employment systems starting with the stage of 'economically inactive' as the most distant from the labour market through to 'securing employment'.

Although the disregard of earnings should significantly reduce the financial disincentives at the stage of 'securing employment', disincentives may arise at other stages. For example, 'job search' could include people who lose their job and are looking for another, becoming liable to pay a new or higher charge because they no longer receive earnings, when their income may have dropped significantly. This group could be protected if there was a 'period of grace' (say for six months) following job loss when someone could be treated as if they had earnings and so not liable for a full charge. Similarly the earnings disregard could be extended to cover people who are employed but not receiving earnings, such as during periods of illness, when receiving sick pay.

There may also be financial disincentives at the stage of 'desire for work' where people may be using the 'permitted work' rules, which

Figure 1 Potential barriers within support and benefits/employment systems at different stages of distance from the labour market

■ *Economically inactive*

Estimated 41% of disabled people, 61% of personal assistance users

Support systems

Social services high-risk eligibility criteria

Little expectation that disabled people will work

Benefits/employment systems

Benefit levels and whether better off out of work

Disincentives to work when on benefit, including for couples

■ *Desire for work*

20% of disabled people, 19% of personal assistance users

Support systems

Direct payments may be more flexible for work and job search – but take-up is low

Benefits/employment systems

Lack of information

Importance of ‘stepping stones,’ e.g. rules about working or studying while on benefit

Information and access to training

■ *Job search*

6% of disabled people, 3% of personal assistance users

Support systems

Employment not seen as integral to social care role

Future funding of support package might be affected by a move into work

Benefits/employment systems

Uncertainty about income in work

Uncertainty about ‘linking’ rules
Better-off calculations not always done by advisers

Access to Work could be important but not always well publicised

■ *Securing employment*

33% of disabled people in work, 18 per cent of personal assistance users

Support systems

Staff belief that work may reduce support needs or cast doubt on the person’s disability

Risk of social services support being reduced if Access to Work is arranged

Until 2002, earnings could trigger higher charge

Benefits/employment systems

Operation of linking rule not straightforward

Benefit run-ons

Some experience of delays with Access to Work

In-work benefits and tax credits

Note: Adapted from Gardiner’s typology. Estimates about proportions of disabled people and personal assistance users based on the Centre for Analysis of Social Exclusion calculations

allow someone receiving one of the incapacity benefits to work for a maximum of £20 a week with no hours or time limit, or for up to 16 hours a week for six months if earning less than £66 a week (unless doing 'supported' work or working under supervision). Although earnings are disregarded for charging purposes, as other income such as occupational pension is chargeable, the calculation of whether it is worth working could become more complex and may be considered too risky.

Further research into the specific circumstances, barriers and labour market distance of personal assistance users may be needed in order to develop a comprehensive strategy to address their employment and support needs together.

Being better off in work

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People may not be better off in work if the difference between incomes out of work and in a job is small (the 'unemployment trap') or if people are prevented from taking better paid work, as when earnings rise, benefits are reduced and taxes rise (the 'poverty trap').

The 'unemployment' trap can particularly affect people with high living costs. Some disabled people may see little gain from working; some people out of work had very similar living standards to people working with in-work benefits (Rowlingson and Berthoud 1996).

Some personal assistance users told the working group that they had to earn over £25,000 a year just to meet their costs, which might be feasible for people in professional or managerial jobs but less possible for those who could only work part-time, or in low paid jobs. The disregard of earnings should help to boost disposable incomes for those in work but could also lead to lower disposable incomes for those out of work receiving 'chargeable' income, unless they can demonstrate high levels of disability-related spending.

The 'poverty trap' arises where people lose 32 per cent of their gross earnings in tax and national insurance, rising to 70 per cent as Housing Benefit, Council Tax Benefit and tax credits are withdrawn. Had 55 pence in the £ been applied to earnings for charging purposes, this would have meant a net return of 30 pence from each £1.²⁰ The disregard of earnings means that the poverty trap for personal assistance users could be improved, as disposable income will not be further reduced by having to pay for support.

5 The objective of a 'level playing field' and key principles

Chapter summary

The working group believed that a key objective should be to create a level playing field between those who need support and those who do not. A level playing field could be particularly important for people whose need for personal assistance arises early on in life as they will not have had the same opportunities for earning and saving for old age as people without those support needs.

From this objective, the working group identified nine principles to inform future policy options:

- People with support needs should have the opportunity to work and to progress in work, and without financial penalty.
- Access to funding for services and payments, and charging policy, should be consistent across the country.
- People with support needs should not be financially penalised by living with a partner, nor should the partner face financial disincentives to work.
- Any system of funding a level playing field for personal assistance users should not result in a more limited service (such as through changes to access or eligibility) for other service users.
- Any system providing support should be as simple, accessible and predictable as possible.
- Funding should cover all aspects of support needs, including all that is necessary for disabled people to operate as good employers when recruiting their own assistants.
- People receiving personal assistance should be supported to use the money effectively.
- People receiving funding for support should be accountable for what they receive.
- The accountability of funders should be transparent.

The current system fails to match up to all of these principles, although changes to the means tests for the Independent Living Fund and local authorities go some way towards meeting the principle of work opportunity and relationships without financial penalty. There may also be some improvement in consistency and the Independent Living Fund changes should not affect other users if additional grant aid is available. However, local authority changes could have an impact on other groups if councils lose revenue from charges as a result of the new system. The system is likely to remain complex and difficult for users to predict, but the overall impact of the recommended local authority means test is difficult to estimate.

Having reviewed the problems faced by disabled people caught in the ‘personal assistance trap’, the working group was concerned to set out some objectives and principles to inform discussion of policy options.

The objective of a level playing field

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The group established that the main aim should be to create a level playing field between people who use assistance and those who do not. This was considered a more appropriate objective than, say, preventing residential care or alleviating poverty (although these objectives could be important in other contexts).

In relation to the ‘personal assistance trap’, the group felt that a level playing field meant that **‘people with support needs should not be financially worse off than others who do not receive that support’**.

The need for a level playing field in personal assistance may vary across different points of the lifecycle. For instance, people who need personal assistance from an early age could have potentially shorter working lives if they have an impairment or condition which deteriorates and work is no longer possible. Someone in this position may find they are living on a lower pension entitlement than someone who has not had to retire early. They may also need to build up a higher level of savings than someone who expects to leave work around age 65 because of the extra years of retirement and to pay for adaptations, equipment or additional support. Hence the assumption (noted in Chapter 2) that savings can be used to pay towards a support package can make it more difficult to achieve a level playing field. Application of a level playing field early in life might also help to extend the length of time someone works, having a better early start (for instance, through identifying greater training opportunities) at a young

age. Having longer work experience could also help promotion prospects and enable someone to compete more successfully in the labour market, even if their working life is shorter.

As well as gains to the individual there could be gains to society. The overall cost to the state could be halved if a personal assistance user was in work compared with being out of work. It is possible too that more flexible provision at a younger age might reduce demands on support services later on in life (Zarb 1998).

Through discussion the working group identified principles which would need to be met in order to deliver the overall aim of creating a level playing field.

Principles

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Nine principles were discussed, each covering different aspects of policy or delivery or applying equally to both. They are presented here not in order of priority as such (difficult as it would be to prioritise one over the other) but principles that have most emphasis on policy (or both policy and delivery) first, followed by those with greater relevance to delivery. As general principles, they are ideals or aspirations, and can be used to measure progress towards a level playing field. We consider the extent to which existing structures match up to these principles at the end of this chapter and specific elements of the current system in Chapters 6 and 7.

People with support needs should have the opportunity to work and to progress in work without financial penalty

People who need personal assistance should not be disadvantaged by the historical assumption that they do not want work. Personal assistance users should have the same opportunities as other people to obtain work and to progress up the career ladder. This would include being encouraged in their work aspirations, the support to achieve them, as well as not having greater financial penalties to earning than those faced by people who do not need personal assistance.

Access to funding for services and payments, and charging policy, should be consistent across the country

If someone needs personal assistance to go about their daily lives, whether those needs are met should not vary by where they happen to live. This should apply to both the support itself, and the extent to which users are expected to pay for it. Inconsistency in levels of support, or requirement to pay for it, creates inequity between personal assistance users in different parts of the country and between those who use personal assistance and those who do not, as the latter do not face this kind of disincentive to moving in pursuit of work or promotion.

People with support needs should not be financially penalised by living with a partner, nor should the partner face financial disincentives to work

People who use personal assistance should not be penalised for having a family and personal life. A partner may already be meeting some support needs (unpaid), and so making a financial contribution towards the rest of the support package could place additional strain on relationships. Neither personal assistance users nor their partners should be penalised by service providers taking partner's incomes into account as available to pay for support.

Any system of funding a level playing field for personal assistance users should not result in a more limited service (such as through changes to access or eligibility) for other users

Put simply, the creation of a level playing field for one group of personal assistance users should not deliberately disadvantage another group of people with support needs. If individual users do not pay, or pay less for support when they receive it, and as a result other users had to pay more at the point of delivery or receive a lesser service, this could lead to a more uneven playing field between different groups of people who need support. In essence, more resources would be required.

Any system providing support should be as simple, accessible and predictable as possible

People with support needs should be enabled to obtain services or payments to meet those needs. Service providers and funding agencies should operate simple procedures which are consistent across providers, and ensure that their services are accessible to the people who need them. Systems of support, as well as any financial contribution towards them, should be as simple and predictable as possible to enable individuals to make informed decisions about everyday matters like moving or working in full knowledge of the implications of such decisions for their support package.

Funding should cover all aspects of support needs, including all that is necessary for disabled people to operate as good employers

People should have enough support so as to cover their needs. In particular where people receive a direct payment to recruit their own assistants, it was considered important to have sufficient to allow them to be a good employer and comply with the relevant legislation. This includes health and safety (such as European directives on lifting and handling) and employment legislation (including payment of National Insurance contributions, sickness and holiday arrangements, tax credits for personal assistants, etc.).

People receiving personal assistance should be supported to use the money effectively

Those who employ their own personal assistants may need technical advice about how to fulfil the requirements of being a good employer, as well as general peer support. Personal assistance users should be able to obtain advice so as to use their support to best effect.

People receiving funding for support should be accountable for what they receive

Personal assistance users, particularly those who receive payments, should be accountable for the public money they receive in lieu of services. Monitoring systems should be designed so as to require the least possible bureaucracy for the users, which is consistent with accountability and transparency of funding. Accountability requirements should be as streamlined and standardised as possible.

The accountability of funders should be transparent

It is clearly important to know how public money has been spent, and the accountability of funding agencies should be transparent to the public and to personal assistance users. Processes should be as standardised as possible and include mechanisms to involve user representatives.

How the current system matches principles

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In this section we take an overview of current arrangements for support at home and at work to see how it matches against our principles.

People with support needs should have the opportunity to work and to progress in work, and without financial penalty

The inclusion of earnings in the former Independent Living Fund and local authority means tests gave little incentive to work. The disregard of earnings should now go some way towards meeting this principle by reducing the disincentives (and might also have some symbolic value in indicating that people who use assistance may wish to work). However practice guidance suggests that work-related spending only be allowed if exceeding the net income from employment, which may not meet this principle.²¹ Other barriers and anomalies may also need to be addressed before this principle is fully met (see Chapters 4 and 8).

Access to funding for services and payments, and charging policy, should be consistent across the country

Variation by area and between functions and agencies can lead to people with potentially similar needs having different support packages and financial contributions. Support needs may remain the same but if

someone moves from one part of the country to another they have to reapply for Access to Work (and so may face delays in reassessment and provision). Someone may be faced with different eligibility decisions for the support package (while criteria are consistent, a line can be drawn according to local circumstances) and a different charging regime. While the Independent Living Fund operates the same system across the UK, and so can 'smooth' some of the local variations, there remain some differences between the Fund's means tests and local authorities'.

The government has stated that local people value the ability of their elected councils to make decisions on charging policies; as a result the influence of local personal assistance users and disability organisations could be crucial (Baldwin and Lunt 1996). Department of Health guidance on charging and Fair Access to Care (see Chapter 7), may lead to some consistency across localities but is unlikely to meet this principle as local authorities retain discretion about whether to charge and some of the elements of charging (see Chapter 5).

People with support needs should not be financially penalised by living with a partner, nor should the partner face financial disincentives to work

Support from partners may already be reducing the costs to the state (see Chapter 2). The inclusion of a partner's income within a means test for support created work

disincentives for the partner, as well as discouraging living with a partner. The exemption of partner earnings should reduce a partner's work disincentives which meets some of this principle. However, as other incomes of a partner can also be charged against, unless offset by disability-related spending, this principle may not be met in full.

Any system of funding a level playing field for personal assistance users should not result in a more limited service (such as through changes to access or eligibility) for other users

Support is funded by a mix of sources, grant aid to local authorities and the Independent Living Fund, financed through general taxation and users' contributions. The working group was concerned that, in the absence of changes to central government financing of support providers like local authorities and the Independent Living Fund, those services could face a shortfall in funding which they might be tempted to make up by introducing tighter conditions of eligibility affecting other users, or require other users to pay more, especially in the light of the budget shortfalls noted in Chapter 2.

The Independent Living Fund changes should be met through additional grant aid from the Department of Work and Pensions. There is no additional funding for local authorities to meet the new charging system, although practice

guidance suggests that there could be revenue gains through improved benefit take-up (in effect, the Department for Work and Pensions would meet the increased cost). However if councils lost revenue as a result, there is a risk that they could seek to charge other users, or to reduce the level of service (perhaps even dropping below the minimum threshold for the Independent Living Fund). Whilst the impact of a new complex means test in its entirety is uncertain (discussed more fully in Chapter 6), reforms to the Independent Living Fund appear more likely to fully meet this principle.

Any system providing support should be as simple, accessible and predictable as possible

Personal assistance users may have to deal with several complex systems, as described in Chapter 3, each of which may affect the other or are subject to different funding influences, and so not always predictable for individuals. The different rules applied by local authorities and the variable frequency of monitoring and review, coupled with the pressures of local political control and the annual budget process, often led to individuals feeling uncertain about the security of their support package, in addition to the insecurity often felt about the benefits system. Although possibly more consistent geographically if enough councils follow the Department of Health guidance, changes to the local

authority charging regimes could result in a more complex system administered by each local authority. The introduction of disability spending assessments may also make the overall impact of the systems less simple and predictable for users.

Funding should cover all aspects of support needs, including all that is necessary for disabled people to operate as good employers

Payments may not always be enough for the individual to meet all the costs of being a good employer; as well as local authority budgetary constraints, the two Independent Living Funds have maximum ceilings on payments, and this can particularly affect people with very high support needs (say at night) as they can quickly reach the ceiling.

People receiving personal assistance should be supported to use the money effectively

People can be faced with several complex systems, in some cases recruiting their own personal assistants as an employer. However, the coverage of support schemes is not uniform across the country.

People receiving funding for support should be accountable for what they receive

People can be accountable to each system for the money or services they receive. In some cases this can mean accounting to three or more systems at regular intervals.

The accountability of funders should be transparent

The agencies that fund personal assistance costs are currently accountable to different parts of government. The Independent Living Funds and Access to Work are accountable to different divisions of the Department for Work and Pensions, and then to Parliament.

Local authority social services departments are accountable to the Department of Health in relation to social care but also to the Department for Transport Local Government and the Regions for local authority funding, as well as the local electorate through council members.

6 Options for setting a financial contribution

Chapter summary

The working group considered a range of options for paying for support packages. *Removing contributions for support at the point of use* was considered the option most likely to achieve a level playing field and match up to the principles, although it was recognised that this was unlikely in the short term because of the potential cost.

The group then considered alternative options:

Improving means testing was the approach adopted by government. The cumulative impact of the new charging regime is difficult to predict, however financial disincentives to work or to save should be reduced. Offsetting disability spending could help people with chargeable income, and the Income Support ‘buffer’ could protect those on lower incomes. The principles of work and partnerships might be met in part, but other principles may not be met if, as a result, the system became more arbitrary and complex, or if inconsistently applied across the country, or if affecting other users.

A further option, *setting a contribution without a means test*, would probably entail a minimal charge against disability benefits which are intended to help towards the costs of disability (as done nationally by the Independent Living Fund and a minority of local authorities). Whilst this would be simpler and more consistent across the country, if there were some resource implications, additional funding would be required so as not to penalise other users. If support services are fragmented, a ceiling or integrated charge across all sources of support may be needed.

Overall the preferred options were to change the way that contributions are assessed, rather than increasing incomes to help someone pay for support.

In this chapter we describe some of the alternative options for paying towards support packages. We first consider the option of removing the financial contribution (support packages being free at the point of use), then improving means tests, and finally options for setting a contribution without undergoing a means test.

Option 1: Removing financial contributions for support packages

Personal assistance free at the point of delivery has been suggested as an important solution because of the analogy with health care and because disabled people have no choice but to use personal assistance. The arguments against further charging in health care can also apply to personal assistance, i.e. charges reduce or delay service use, possibly resulting in higher costs in the longer term, can create inequity between those exempt and those just above the threshold, and increase the proportion of funding from the unhealthy, the poor and the old.²²

Funding support

The objective of charging individuals has been to improve services (a higher priority than making services 'free').²³ Behind that objective is the sentiment that people who use a service should pay for it directly rather than funding by taxpayers more generally. However, many

disabled people already view charges as a 'tax on disability' especially if they are income tax payers or council tax payers and have already made a contribution. Improving services may be less straightforward as an objective where someone receives a direct payment, and so purchases their own services.

The provision of free support services would still require someone to pay, but not the person receiving assistance when needing it. This suggests that the additional cost would have to be borne either collectively by the taxpayer on a 'pay as you go' basis (such as general taxation), or through compulsory, funded social insurance (Joseph Rowntree Foundation Inquiry 1996). It was felt by the working group that the most appropriate funding for support should be collective rather than by individual users at the time of need. This is because assistance with essential daily living tasks is not a matter of consumer choice but basic need (over which someone has no control), and so could be distinguished from other local services for which people might pay a charge. Collective funding may also be the only way to prevent people from being financially penalised as service users if they are charged for services when receiving them. This essentially depends on the willingness of others to pay for such support.

However, the government has also accepted that some support (in England) will be free at the point of use – but only for short-term needs, such as temporary supported accommodation, and home care received as part of an intermediate care package (normally six weeks). This was done in part because of the amount of administration generating little or no income, and not to affect take-up of intermediate care.

Free personal care at the point of use has also been approved by the Scottish Parliament, but only for older people, not working-age adults (but this may be reconsidered). ‘Personal care’ is likely to broadly follow the definition in the Royal Commission on Long Term Care.²⁴ It includes personal assistance with dressing, getting in and out of bed, but general living expenses, including domestic help, would still attract a charge (Care Development Group Report 2001). It will be part of a package of community care reforms and includes the aim of improving services as well their inevitable expansion when services become free.²⁵

This option was considered by the working group to be the ‘ideal’ aim. A variation of this option would be retaining charges for some services like meals, which all people, disabled or not, have as a daily living cost.

Impact on providers

Although charging is not directly intended to deter people in need of services from access to them,²⁶ the evidence suggests that having to pay can lead to reduced use of a service. Conversely making a service free at the point of use would increase demand by existing service users increasing the frequency of the support they receive, and perhaps by people currently paying privately switching to a free service.²⁷ Estimates about service demand were modelled for the working group by the Centre for Analysis in Social Exclusion, using data from the 1996/7 Disability Follow-Up to the Family Resources Survey. This data has limitations in that the definition of ‘personal assistance’ is based on identifying services like home care, laundry services, private domestic help, day centres and meals on wheels. Numbers are small, and so the figures should be seen as estimates rather than definitive figures. Notwithstanding these limitations, the data suggested that there could be a rise of between 6 per cent and 22 per cent in new service users, or those wanting more services, if charges were reduced or removed (see Table 2).

Increased demand on services could lead to a significant reduction in local authority income – we noted in Chapter 2 that in one authority one-fifth of the home care budget was recouped in charges. If local authorities were to bear the cost

Table 2 Number and percentage of new or more intensive service users if charges were reduced or removed

By income group

	Scenario A		Scenario B		Scenario C	
Bottom fifth	22,800	(10%)	75,500	(34%)	145,000	(66%)
2	17,900	(5%)	-		25,600	(6%)
3	26,800	(10%)	-		34,300	(13%)
4	12,000	(8%)	-		53,400	(35%)
Top	2,400	(2%)	-		-	
Totals	82,000	(7%)	75,500	(6%)	258,500	(22%)

By severity of impairment

	Scenario A		Scenario B		Scenario C	
OPCS 1–3	22,100	(7%)	21,400	(7%)	183,200	(61%)
OPCS 4–6	25,700	(7%)	25,700	(9%)	28,900	(8%)
OPCS 7+	32,100	(8%)	32,100	(7%)	41,500	(10%)
Totals	82,000	(22%)	75,500	(6%)	258,000	(22%)

Source: Centre for Analysis of Social Exclusion estimates for the working group based on the Disability Follow-Up to the Family Resources Survey 1996/7

Notes: Includes people over age 65

Scenario A – those who say they need additional services but can't afford them increase their use in line with other service users

Scenario B – use of services by those in the lowest income group rises to the average for people in other income groups with similar levels of impairment

Scenario C – use of services by all income groups increases to the average for people in the top income group with similar levels of impairment

themselves some additional compensatory funding would be necessary from central government (perhaps, for example, through adjusting the standard spending assessment formula). However, variation in eligibility criteria for services and different charging systems across the country could mean that an across the board increase to local authorities might fail to make adequate compensation to some authorities who are collecting a high amount of charge income, whereas other councils (such as the minority which do not charge) could be over-compensated. In contrast, compensation for additional Independent Living Fund spending would be relatively straightforward (by increasing grant aid).

The advantages to providers of removing charges would be lower administration costs (perhaps by up to 20 per cent of current costs for local authorities, less for the Independent Living Fund as its administration costs are already low (2.8 per cent)). It may also remove shunting between councils and the Independent Living Fund, as noted in Chapter 3, contributing significantly to the desired development of a seamless service. It might also be easier to manage pooled budgets between health and social care without having to identify social care separately for charging purposes. On the other hand, the increased demand on service providers and

greater financial pressure on local authorities might lead to services being restricted. There might also be a danger that some disabled people might be considered too expensive for the community and end up in residential care.

Impact on individuals

Making assistance 'free' at the point of use for all users would have most impact on people over pension age as this is the group most likely to receive and pay for local authority services (see Chapter 2). Others gaining most would be those paying most under the current system, i.e. better off and more intensive service users. As such it would have a wider impact than people who were the main focus of the working group, as those caught in the personal assistance trap tend to be mainly under age 65.

Matching up to the principles

Assistance free at the point of use could be the easiest method to achieve a level playing field between those with support needs and those without. It could remove one of the barriers to working and living independently. It should also allow opportunities for work and to live with a partner without being financially penalised. Being consistent across the country, it would meet the principles of consistency and simplicity and allow people to move without concerns about different payment regimes.

However, it could have an impact on access to services with greater demand from new users and those increasing their level of service, and so could fall foul of the principle that improvements for personal assistance users should not be at the expense of other users. It might also have a knock-on effect in reducing the amount of support to individuals and so not meet the principle of funding covering the costs of support, including being a good employer. Hence considerable additional resources would be needed. It was recognised that the political and cost reasons outlined above indicated that this might not be feasible in the short term. Hence the working group considered interim options.

Interim options

The working group explored two contrasting approaches; first, improving on means-testing; and second, on setting a contribution related to income but without going through a means test *per se*.

Each approach involves a series of trade-offs between issues of complexity, simplicity, consistency and equity. The more differentiated a charging system, the more costly its administration and the more difficult for users to understand (Kestenbaum 1997). It may become reliant on the discretion of staff, which in turn can lead to concerns that users are not being treated equally. On the other hand, a set formula might be easier to

understand and administer, more consistent across different service providers and localities, but may be less responsive to individual needs and circumstances.

Option 2: Improving means testing

Most means tests consist of deciding **what counts as income**, what **outgoings** can be taken into account (allowing additional costs like housing), and **how much of the available income left over the threshold** should be considered as available to pay a contribution. Improving means tests entails making changes to one or more of these different elements, each with potentially different effects. This 'better means-testing' approach has been adopted by the Department of Health, adjusting each of these elements, which may have a different impact on personal assistance users, and a cumulative effect on both individuals and local authorities. The Independent Living Fund changes the element of what counts as income.

What counts as income

Earnings: Most means tests include earnings as income, so the new disregard on earnings is welcomed. It is believed to have little revenue implications for local authorities (as so few users in each area are working, and because information from two councils indicated that income derived from earnings amounted to

less than 2 per cent of all income from charges).²⁸ However, the gains to individuals wanting work or moving into a job could be considerable (see also Chapter 8 for anomalies remaining).

DLA: Although most means tests disregard DLA, some councils have taken it into account as being available to pay for support, which in some cases left users below Income Support levels. Department of Health guidance states that councils which do count DLA will have to undertake an assessment of the individual's disability-related spending. The Independent Living Fund counts half of the DLA care component as a minimum contribution (issues about using DLA are further discussed under Option 3 in this chapter).

The Severe Disability Premium: Normally part of the calculation for means-tested benefits, it is assumed to be available to meet support needs and so is taken into account in full by both local authorities and the Independent Living Fund (this will not change in 2002). There has been little indication of whether it is intended specifically to pay for support or, reflecting its origins, for domestic assistance (which most councils no longer provide) (Kestenbaum 1997). It is payable to people who are technically living alone, and where no one receives a carer's allowance for looking after them. In effect, people who live alone are paying higher amounts; in 2001,

someone living with others or who was assessed by the Independent Living Fund as paying the minimum contribution, would pay half DLA (£26.75), whereas someone receiving Severe Disability Premium would also pay 100 per cent of the premium (£66.95). It is only payable with means-tested benefits (not the Disabled Person's Tax Credit) so people in work would only be charged against the Severe Disability Premium if receiving it in Housing or Council Tax Benefit.

Savings: It is also often assumed that capital can be converted into income to pay for support packages, so people with savings can find their support is reduced or withdrawn. The Independent Living Fund previously reflected Income Support rules, although where savings were above that limit, any amounts earmarked for disability-related equipment or adaptations could be ignored for a period (often six months), pending purchase. Savings limits can affect someone's ability to purchase other essentials, such as a deposit towards a suitable home, or an adapted vehicle. From 2002 the limits will be more generous; savings under the lower limit (£11,500) will be ignored; savings above the upper limit (£18,500) exclude someone from support; and between the two limits, it is assumed that an income of £1 is gained from every £250 of savings (called 'tariff' income). If councils take savings into account they should consider circumstances where

individual users have particular needs for savings.²⁹

Making allowances for outgoings

Using Income Support to calculate the level of income above which someone is expected to pay implies a low threshold as Income Support is the basic safety net benefit. The Independent Living Fund uses the basic Income Support personal allowances (except the Severe Disability Premium) but adds on allowable expenses such as rent less housing benefit, mortgage repayments, an allowance for school meals for any child at school and a standard rate of interest for any loan repayment for disability-related adaptations to the home. Local authorities have not always included outgoings such as housing or disability-related costs, and so people could find their disposable income falling below Income Support as a result of paying a charge.

Offsetting disability-related spending

Unlike the Independent Living Fund, if local authorities take any DLA into account after 2002, they must also undertake an assessment of the person's disability-related spending; those that do not take DLA into account are nonetheless expected to consult their users on whether they should undertake spending assessments.³⁰

Although not a comprehensive list, the types of costs envisaged in the Department of Health guidance include community alarms and privately arranged services, equipment or travel (including to enter or remain in work), personal assistance costs, plus the costs of 'speciality' items such as special diets or clothing, including heating costs 'above average for the area'. Spending is to be individually assessed by a personal interview in the user's own home and should also include benefits advice. Evidence of actual spending may be requested, although local authorities are to have some discretion in how this is done; if receipts have not been kept they might be requested for future spending. Torbay is an example of this approach (see box).

A system of 'standard' and 'special' allowances (i.e. depending on individual circumstances) could be developed, along the lines of Ann Kestenbaum's research. Standard allowances covered disability specific items (such as wheelchair maintenance and equipment) as well as notional amounts for extra spending on heating, laundry, clothing and food (an extra £5 per week to cover the inability to shop around). At 1997 prices, the upper range of standard allowances alone could amount to around £140 a week (Kestenbaum 1997).

Torbay: Disability related spending assessments

The Torbay scheme, highlighted by the Audit Commission and the Department of Health as an example of good practice, bases its charging system on an individual financial assessment which includes links with the Benefits Agency, council staff being trained and accredited to facilitate national benefits. Social workers and care managers are not involved in the financial assessment. The first year of the scheme generated 1,150 new benefit claims and increases to existing benefits for over 750 users. The level of appeals was minimal, with only 26 users asking for a review in the first 12 months. Resources generated by charging were estimated to have increased by £376,000 pa, and the administration costs amounted to 10 per cent of the income raised from charges. As a result of the assessment around 30 per cent of users have their charge reduced to zero. A third of users have spending of below £20 per week, a third over £40 a week.

Alternatives to a disability spending assessment would be a 'costs' buffer, similar to the 'grant premium' in Disabled Facilities Grants. A buffer was used by some local authorities in the 1990s, fixed by a proportion of DLA, extra costs only being considered in more detail if the users requested a review (similar to Option 3 discussed below).³¹

Changing assumptions about income available to pay for support

The Independent Living Fund financial contribution was based on Income Support, where 100 per cent of the person's income above that threshold (plus housing and related costs) was assumed to be available to pay a contribution towards their care package. Department of Health guidance has indicated that it is inconsistent with the objective of promoting independent living to assume that all of a users income above basic Income Support levels should be available for charging, hence a 'buffer' of 25 per cent should be added to the basic Income Support calculation.³² An alternative might be taking a percentage of available income as a maximum charge (Griffiths 2000). However, a buffer might give more help to people on low incomes.³³

Impact on providers

The costs of administering an individually-assessed system is usually higher than a standard formula approach, although it has been suggested that using specialist finance staff may produce assessments more accurately and quickly, freeing care managers to use their professional skills more appropriately – the latter being paid on a higher grade than finance staff.³⁴ Indeed, increasing the take-up of disability benefits is considered likely to generate higher revenue for councils.³⁵

Local authorities are concerned that it could be time consuming and costly to administer, might generate more appeals, and lack clarity for users.³⁶ One authority had ceased undertaking disability costs assessments, in part because of high administration costs and a reduction in charge income. The original Independent Living Fund contained the discretion to offset disability-related costs where applicants were not on Income Support, although this became more difficult to operate as the Fund became bigger (Kestenbaum 1993). Local authorities could lose revenue if a significant proportion of their users receive Income Support, have high costs, or disregarded income.

Impact on individuals

In general means tests protect people on low incomes from having to pay a charge which could reduce their disposable income and lead to hardship. Disregarding one source of income (earnings) should help people in work or considering work, but might as a result place additional pressure on other sources of income such as occupational pensions and other benefits. By offsetting disability costs, people with high disability-related spending but with income that is taken into account or higher than the threshold should be protected. The Income Support 25 per cent buffer should protect people just above the Income Support threshold. Some individuals may gain, for instance, people who can

demonstrate high levels of verifiable spending could gain more compared with those who choose to spend less or go without, or who cannot prove their spending. Linking assessments to benefits advice means that the individuals can gain from increased benefits, and the scope for take-up appears considerable.³⁷ A detailed assessment could be an unnecessary and intrusive additional level of bureaucracy, especially where the service provision is at a low level and/or the charge is acceptable to the user (Kestenbaum 1997).

Matching up to the principles

The cumulative impact of these changes is uncertain; in particular, the assessment of disability-related spending could be controversial and complex, and is largely uncharted territory in means tests (and so will need to be monitored). By including additional expenses to be offset, people on low incomes but with a potentially high charge could be protected, but this may be at the cost of the principle of simplicity and predictability for users.

By ignoring earnings in the calculation of income the principle of work opportunity can be met. Consistency across the country might be improved if local authorities follow the Department of Health guidance although discretion about whether or not to charge, and some aspects of charging (such as including savings) remains with the local authority. Where a partner is

working, some of the existing financial disincentives will not apply, so the principle about not penalising partnerships could be met in part.

As noted in Chapter 5, changes to the Independent Living Fund should be grant-aided by £3.6 million, and so meet the principle of not affecting other users. However, the impact on local authority revenue is unclear, and there is no additional funding to meet any shortfall in revenue from charging. There is concern that if councils do lose revenue they may be faced with the prospect of increasing charges against the remaining sources of income that are chargeable, or reducing the amount of support received by existing and new personal assistance users, or tightening the eligibility criteria. Means tests can also be experienced by individuals as intrusive which, if deterring them from access to the services they need, would mean that the principle of simplicity and accessibility could not be met.

Option 3: Setting a contribution without a means test

The working group examined whether it was possible to have a simpler system where people paid an affordable contribution, where providers could easily identify individuals and the appropriate charge to be levied, without a separate means test. As discussed in

Chapter 2, some local authorities have set a charge (sometimes coupled with a maximum payment) based on the type of income received.

DLA as a trigger

In the absence of a means test (Option 2), the only other realistic ‘income trigger’ is probably DLA. One example of this approach is the Independent Living Fund minimum contribution, taking half of DLA from each client across the whole of the country (although of course there is an additional financial assessment, as discussed above). This was also favoured by the ‘Let Us Work’ campaign during 2001, when payment from DLA was preferred to levying a charge on earnings.

This is considered reasonable as DLA is a contribution towards the extra costs of disability (Department for Work and Pensions 2001). Many local authorities had also assumed that the DLA care component was available to contribute towards the costs of support, though some demanded 100 per cent of the benefit payable (Griffiths 2000). However, DLA is intended to cover the costs of disability generally, not exclusively support costs, the conditions of entitlement for care and mobility being simply the means of identifying eligible people.³⁸ Hence, a ceiling of 25 per cent of DLA has been suggested to allow for additional costs to be met (Watson and Griffiths 1999). As a result, some people are concerned about taking DLA as

chargeable income, especially in the light of a court case indicating that councils should not take account of DLA payable in respect of night care unless they are actually providing services at night.

In future it will not be possible to take DLA as chargeable income without undertaking a disability spending assessment.

However, the working group considered the implications of using DLA as a trigger for a charge, as undertaken by the Independent Living Fund and one local authority, Kingston upon Thames. The Kingston scheme in 2001 is presented here not as an ideal approach but to illustrate that a local authority can operate a non-means-tested system collecting relatively small amounts from each user, whilst generating enough revenue with limited administration costs. Other authorities which use DLA as a trigger have imposed higher charges on individuals, causing hardship, which was not an approach favoured by the working group. Key aspects of the Kingston approach (Figure 2) included set charges related to the level of DLA received, individuals paying around 60 per cent of their DLA.

As with Torbay, a key plank when charging was introduced was linking to welfare rights advice. Overall, 15 per cent of spending was recouped in charge income, but only 6 per cent of the specific Independent Living

Scheme budget – perhaps because people on that scheme had larger packages of support. The costs of administration were less than 1 per cent of income generated, and there was no reported problem with collection (98 per cent collection level). Staffing levels included one administrative assistant within home care to do charges/bills to enable queries to be quickly and easily dealt with, rather than a distant finance section. A small number of users had their charges waived, most of whom were not getting DLA and where charges would result in income being reduced below Income Support levels. People had to ask for a financial assessment if they could not pay. Kingston's policy was originally devised in consultation with users and was considered easy to understand and administer, brought in a high level of income, and was seen as fair as it did not penalise users who worked or needed higher levels of service.

Impact on providers

In requiring providers simply to identify the level of DLA received, this option would be simple and cheap to administer. As it implies a relatively small charge being levied on each person, there is a risk that the income generated would be low and lead to pressures on local authority and Independent Living Fund budgets (though to a lesser extent than Option 1). However, evidence from Kingston indicates that, contrary to expectations,

Figure 2 Kingston's charging policy 2001/02 in outline***Home care: personal and practical***

	On means-tested benefit	Not means tested
Receiving minimal ³⁹ care	£6.10	£10.60
More than minimal and not DLA/AA	£6.10	£10.60
More than minimal and gets DLA/AA		
DLA lower rate	£8.75	£10.60
DLA middle/AA lower	£22.05	£22.05
DLA highest/AA higher	£33.05	£33.05
Claiming DLA/AA awaiting outcome	£6.10	£10.60
Home care – shopping	£6.10 (free if also paying home care charges)	
Home care – laundry	£2.05 per week of service	
Mobile meals	£2.75 dinner and sweet	
Careline	Free to those receiving home care or means-tested benefit, or £3.30 per week	
Day care	Free to people receiving home care or £6.10 per week plus meal charges	
Respite care	Up to maximum charge of £115.90 per week	

enough income could be generated from this type of option, although proportionately less from the Independent Living Scheme (consisting of predominantly higher intensity users) than from home care. An element of discretion may also be needed to allow for charges to be reduced or waived if people would face hardship because of high costs.

Impact on individuals

People who are more frequent users of personal assistance might gain most from this option, as the charge is not directly related to the amount of service they use. It is likely to be simple and predictable for the user. No information about partner's income or savings would be necessary.

Currently in most cases there is no 'double charging' by the Independent Living Fund and local authorities. New charging regimes (such as Supporting People) need to ensure that there is no double charging or potential further demands on sources of income like DLA. A 'seamless' approach to charging has been suggested so that one system aggregates the cost of support, personal care and home care and produces a unified charge (Griffiths 2000) (see also Chapter 7).

Matching up to the principles

This option would go some way towards creating a level playing field as it would not penalise people who were working or living with partners as neither would be a relevant consideration. It would be more consistent than means-testing options provided the percentage of DLA to be taken into account was standardised. It would also be simple and predictable and should not deter people from obtaining access to the services they need. However, if it generated further demands on services (though perhaps to a lesser extent than Option 1), the principle of not affecting other service users might be at risk, thus raising similar concerns as with Option 1.

Increasing incomes

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Other options of increasing the incomes from which personal assistance users would pay a charge were considered too problematic. It

was felt preferable to concentrate on changing the charging systems themselves as the more direct and simplest way to tackling the issue at source and producing more uniform results. Methods of increasing incomes could include building on existing models such as DLA, tax credits or tax allowances, and making costs tax deductible. These were thought to have the disadvantages of being complex and bureaucratic, perhaps adding onto an already complex system.

Tax credits might also be insufficiently responsive to changes in personal assistance needs. They would also be less visible or predictable for users, and could raise questions about how much of the charge should be covered – unless paid in full there could be inequity across the country. While there might be additional objectives for using such income vehicles it was felt that they were not appropriate for the purpose of helping people to pay for their support needs. Hence the approach of increasing incomes did not sufficiently match up with the basic principles for the group to pursue in detail. Indeed disregarding earnings in a means test was thought to be simpler and clearer, and a more straightforward way of improving work incentives across a wide spectrum of earnings than, for instance, adding elements to the Disabled Person's Tax Credit (or, from 2003, the Working Tax Credit).

7 Options for integrating support services

Chapter summary

Problems with the way support is currently delivered indicates there is a need for greater consistency of outcomes across agencies and across localities. Arguments for a more centralised approach stem from the emphasis on more consistent outcomes, statutory responsibilities for groups of people rather than localities, and user and public opinion in favour of reducing postcode lotteries. One option for the longer term might be the development of a 'seamless support service', bringing together the range of personal assistance support at work or at home, within a central system. 'Models' include building on the Independent Living Fund or Care Trusts. Another option in the shorter term includes shared procedures, building on current initiatives for a single assessment between providers of support, and information sharing for monitoring and accountability.

In this chapter we examine the implications of a level playing field in relation to aspects of how support is assessed and delivered.

It may be possible to distinguish between different activities involved in providing support to people who need assistance:

- 1 Assessing the need for support.
- 2 Delivering support (through cash or services).
- 3 Providing support.
- 4 Funding for support.

At present, each is operated at a variety of levels. Both local authorities and the centrally-organised Independent Living Fund make assessments of need and also make cash payments to individuals to purchase their own assistance, although local authorities have the responsibility for delivering services (including to a wider group of people needing assistance than the working group's focus). People who actually provide support to disabled people, whether at home or at work, have to be reasonably local. Finally, current

funding arrangements consist of a mixture of central tax financed support, grant aid to local authorities, council tax and contributions paid by users (the latter being organised both centrally for people supported by the Independent Living Fund and locally for those supported by their social services department). To meet our principles there is a need for more central funding arrangements so that people are not financially penalised by paying towards the support they receive at the time they need it (discussed in Chapters 2 and 6). Here we concentrate on the elements of assessment and delivery.

The objective of a level playing field indicates that greater consistency in assessments and funding requires a more central approach. On the other hand, responding to individual need and having access to support networks to enable people to use payments effectively suggests that provision has to be handled at a local level.

Reasons for a more centralised approach

Many of the complexities and concerns about support packages arise from the assessment, delivery and funding of personal assistance in the context of local authority control, such as eligibility criteria being affected by local budgetary constraints. As a result there is

attraction in a more centralised system for all support needs.

The level of variation has already led to demands for greater consistency nationwide. For instance, more consistent outcomes is one of the objectives of social care policy, and the Department of Health has produced draft guidance to local authorities on a framework for determining eligibility for adult services.⁴⁰ The aim is to ensure that, within a council area, people with similar assessed needs receive services capable of achieving broadly similar outcomes even though the particular form of help offered will be tailored to the individual service user.

Similarly objectives to deliver services for particular groups of people apply nationally, rather than being simply a matter of local discretion, as reflected in the statutory role of social services and in the use of specific grants for social services. Ring fencing is likely to be restricted to areas where the policy goal cannot be achieved by specifying output or outcome targets.⁴¹ User and public opinion is in the direction of more centralised control, as documented by responses to the Independent Living Fund Quinquennial Review as well as some public and expert opinion (Travers and Stoker 2001).

On the other hand, there are drawbacks with a totally centralised approach. National systems can be remote and lack knowledge of local support networks, which as we have

noted above is particularly important for the delivery and provision of support. Independent living also requires links with more locally-provided services like housing. Support services in the home may need to be commissioned from locally-based sources and personal assistance users need to recruit their assistants from within a reasonable travelling distance; a study of direct payments in Norfolk found that many of the Personal Assistants recruited there were women with dependent children, students, and friends of the disabled person (Dawson 2000). Personal Assistance Support schemes are also needed on a sufficiently local basis. The suggestion that local authority support could be made available to Independent Living Fund clients acknowledges the importance of these links (Department for Work and Pensions 2001).

In this chapter we consider long- and short-term options that address some of these concerns and assess how far they match up with principles adopted by the working group.

Option 1: A single, seamless support service

The working group considered whether a more integrated approach might be possible in the longer term, making local delivery more consistent across the country, bringing together the different

functions of support at home and at work.

A single support service for people of working age

We noted in Chapter 5 that a 'lifecycle' approach to a level playing field, emphasising people of working age, could offer long-term gains to society as well as to the individuals concerned. Priority for younger people and those in work was also emphasised in the Independent Living Fund review, in particular pointing to the disparity in income between younger disabled and non-disabled people than between those over pension age (Department for Work and Pensions 2001).

A focus on people of working age would run alongside other developments such as Jobcentre Plus (the working-age agency bringing together benefits and employment provision). A support agency could then deal with employment and support needs holistically. This could be particularly important if some support at work is delivered by way of a direct payment (and so people recruit their own assistants for both work and home). The future direction of the Independent Living Fund, as highlighted in the Quinquennial Review, hints at a similar direction to that of the working group's thinking. The review indicated that there may be greater liaison with other schemes which provide assistance with the costs directly associated with work or education, such as Access to Work

and the Disabled Students Allowance, but do not provide for assistance at home.

This option might entail setting up a new agency, combining the functions of both local authority social services for working-age disabled people and the Independent Living Fund, perhaps also some of the functions of Access to Work (although the different objectives and approach of the current scheme would have to be considered, as well as the broader ramifications of such an option). It should remove 'boundary' problems of people choosing between systems as a result of different approaches to financial contributions, or falling out of eligibility for one system because of the way that services are costed or local criteria established.

This would indicate a central approach to assessment, removing any potential duplication of assessments of support needs and finances. Ideally the single agency would have a nationally-based structure (like the Independent Living Fund) with a single assessment of need, undertaken to national standards and national criteria, to ensure consistency across the country.

Recognising the importance of delivery and provision locally, there would need to be local links for the provision of services or for people to recruit their own assistant, together with local support schemes and peer groups. The suggestions in the

Independent Living Fund review for greater liaison with local authorities could be an important building block for this approach. This approach implies the existence of a central or single budget, replacing the current range of funding streams and funding accountability. Funding for support and any individual financial contribution could be centrally organised (see chapter 6).

Developing Care Trusts

Care Trusts could be one model to build on. They are intended to be a new way of delivering an integrated health and social care service that is 'joined-up', strategic and consistent, intended to be more flexible than existing provision by providing a service that is more tailored to individual needs. Some Trusts may be based on 'social care groups' such as older people or those with mental health problems, though this has not been specified in legislation. Care Trusts can also be formed across more than one local authority area, which can have the advantage of economies of scale. It is possible that this approach could be tested out for personal assistance users of working age, to ensure that their specific needs are met and to link in with other provisions such as Jobcentre Plus and Access to Work.

A single support service for people receiving direct payments

A further alternative would be to have a separate system for people receiving direct payments and

Independent Living Fund payments. This would entail building on the existing Independent Living Fund. While the take-up of direct payments from local authorities has so far been quite low, the proportions receiving cash in lieu of services could expand. Already some daycare activities have been translated into a direct payment to be spent on support workers or however the individual chooses (Wertheimer 1998). Since April 2000, local authorities have taken responsibility for people who have been living in residential care from before 1993 receiving a higher rate of Income Support ('preserved rights'), with the option of direct payments for residents who wish to move into the community. This is likely to affect 65,000 people (25,000 of working age). If assessments are more centralised and more people are awarded cash payments, there may be less need for direct involvement from local providers as it would be the user themselves who would purchase their own assistance locally.

However, this would create a boundary between cash and services, which could reinforce distinctions between the need for 'support' (especially human assistance) and different 'delivery' mechanisms, which might run the risk of leading to a level playing field for some personal assistance users at the expense of others.

A separate service for people with high support needs?

Another approach might be a separate service for a discrete and relatively small group of people with 'high' support needs. The working group examined information about the Swedish system, where people needing at least 20 hours assistance a week had the right to either free services or cash payments from their municipal (equivalent to local) authority. Finance for people needing more than 20 hours was centrally funded (through social insurance). At an early stage, costs exceeded estimates and there was concern about the 20-hour boundary being an incentive for local authorities to assess above that level so as to attract central funding (Barnes 2000). The UK equivalent of a separate service for people with high support needs could be the Independent Living Fund, although there the gateway is receipt of the highest rate of DLA care component, together with a commitment by the local authority to providing £200 worth of services, rather than the amount of hours required.

Adopting the Swedish solution by expanding the role of the Independent Living Fund was not considered feasible by the working group, as this could lead to problems of complexity of definition and administration, and 'boundary' problems created by categorising people as having 'high'

or 'low' needs. It might not deal well with changes in needs (people falling into and out of eligibility), which could lead to further inequity between groups of personal assistance users.

Option 2: Shared procedures

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Shorter-term developments could include shared procedures, even if the current mix of support systems remains. In Chapters 2 and 3 we noted that people could be assessed and reviewed by several different agencies, each requiring their own form of assessment and accountability. The danger is that each agency focuses on its main task and so none sees the 'whole picture', only a small part of it.

Assessments

Personal assistance users can be required to go through two different assessments for their support needs, as well as two means tests to work out how much they should contribute to each agency for their support. For personal assistance at home, people may have to be assessed by both the local authority and the Independent Living Fund to ascertain how much support they need. The local authority assessment may also be different from the Independent Living Fund's, the former having statutory responsibilities for community care, and the latter using visiting social workers to focus on the individual's support needs without any statutory

or contracting role nor any continuing obligation. The process between local authorities and the Independent Living Fund could also lead to delays; some councils could take 13 weeks to do a charging assessment which could have a knock-on effect on the Fund as well as the individual.

Guidance to local authorities now suggests that there should be a single assessment across agencies, coordinated depending on service user group.⁴² Agencies should work together to improve and consolidate a shared culture, common understanding and reliable information sharing, leading to an assessment process that individuals experience as 'seamless and timely'. The Independent Living Fund review also indicated that the Fund would be studying single assessment procedures between health and social services to see whether there might be scope to introduce a similar approach in their dealings with local authorities (Department of Work and Pensions 2001). This would go some way towards reducing some of the potential duplication and delays encountered by some personal assistance users.

Someone might also have to undergo a third assessment by the Access to Work scheme if they are in work or about to enter a job. However, as noted in relation to other options work and work aspirations could form an integral part of an

assessment by other support systems and some 'fast-tracking' across agencies might be feasible.

Separating support from cash inquiries

As has been suggested in Department of Health guidance, a financial assessment does not have to be undertaken at the same time as an assessment of support needs. As both local authorities and the Independent Living Fund undertake their own financial assessments it may be possible for a single financial assessment or for some kind of information sharing to take place, as indicated in the Fund's review.

As indicated in Chapter 6, although the recent changes represent some alignment between the two main support providers (local authorities and the Independent Living Fund) with regard to disregarding earnings and raising the savings limit, there is a case for a more integrated system of charging (to ensure that people are not paying twice from the same source of income). This is particularly important when there are several providers of support. The new 'Supporting People' regime (where a single budget will replace several streams of funding for housing-related support) intends to use the local authority means test where someone receives both housing and other support, which should reduce duplication of charging means tests. Further alignment may need consideration, especially for people

who use both kinds of support, or if additional sources of support are provided.

Standardised accountability

People who are accountable to several systems of support as well as acting as an employer, can find that they need to spend considerable time and effort complying with the different forms of accountability (Chapter 3). There is a case for sharing information or streamlining procedures to reduce the burden on individuals. Similarly the requirement to produce regular returns to show how payments for support have been spent could be streamlined across local authorities and the Independent Living Fund and with the Access to Work scheme. The Access to Work review has already included suggestions for people with no significant change in circumstances having minor renewal processes or managing their own budget.⁴³ Both local authorities and the Independent Living Fund are likely to review users annually so there is a case for reviews to be conducted by one agency for the other or through information-sharing.

Impact of options on providers

Option 1, a single agency, could remove the complexity and duplication of existing schemes, saving on some administrative costs. A central or single budget should streamline accountability and should be more transparent, although there

may be a risk that a more visible budget could be vulnerable to future restrictions. However, a single agency would entail a large-scale reorganisation and change to the structure of accountability, and so would need further detailed discussion with a range of departments about organisational arrangements.

Shared procedures within Option 2 would be more feasible in the short term. This approach could generate administrative savings through reduced duplication of procedures, and reduce delays between agencies. It would also build on some of the existing initiatives taken by local authorities, the Independent Living Fund and Access to Work.

Impact of options on individuals

Individuals could gain from Option 1 if their needs were met in a more holistic way and they were enabled to obtain the support they need at home and at work. However, it might also reduce the scope for 'moving between' systems, as done in the past to minimise the impact of various means tests or eligibility criteria. The shared procedures under Option 2 would help to reduce the level of bureaucracy and complexity in the system which concerns personal assistance users. Under both options, personal assistance users would need

to be assured that they would receive a comprehensive assessment covering all of their needs.

Matching up to the principles

Option 1, of a single agency bringing together considerations of support packages and employment progress, could meet the principles of work opportunity and partnerships. Consistent criteria and a single budget could be more transparent (so meeting the principles of consistency across the country and accountability of funders). It could be simpler and more predictable through bringing different systems and budgets together, meeting other principles. A single agency could also facilitate an integrated financial contribution (if any) (see Chapter 6).

Option 2's sharing procedures should be simpler and lead to greater consistency between agencies. Joint assessments and joint means tests would be simpler and more predictable for disabled people but on their own do not necessarily match up to the other principles. Shared procedures might also help to streamline users' accountability.

8 Key themes and timescales

While welcoming the announcements about disregarding earnings and the direction of the Independent Living Fund, the working group hopes that there are opportunities for further change in policy and delivery to address some of the other issues raised in this report.

The objective of a level playing field and the nine principles considered by the working group in Chapter 5 offer benchmarks measuring existing systems and future progress in this policy area. The principles should ensure that people do not face disincentives to work or live with a partner, have access to simple and predictable systems that provides the assistance they need, as well as peer support to use any cash payments effectively, while not penalising other service users. These principles remain important in the medium and longer term to inform developments in policy and delivery in other fields as well as those directly concerned with employment and support of disabled people.

Key themes

The provision of support at home and at work remains complex and fragmented. The impact of having different support systems can result in:

- Uncertainty surrounding the transition off benefits into work and potential disincentives at different stages of distance from the labour market.
- Complexity creating uncertainty and confusion among users and potential users, as well as 'gatekeepers', like local authority social workers in relation to the Independent Living Fund, and inconsistency of outcomes across the country.
- Potential duplication of procedures across the agencies involved, such as assessment, review, monitoring and accountability of funds, with resulting administrative costs.
- With each agency having its own funding stream accountable to different parts of central and local government, there may be a tendency for 'cost-shunting' or

delays between systems, especially if budgetary constraints are significant concerns.

- Social services support is often difficult to obtain, especially for people from minority ethnic communities and people with learning difficulties. Services need to expand access to these groups to fulfil the requirements of equality legislation as well as the vision of services for these groups.

Remaining employment barriers

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While the disregard of earnings in the calculation of how much someone has to pay for their support should help to reduce the disincentive to work, other barriers to employment remain.

The negative assumptions about the work capacity of personal assistance users in general needs to be challenged. To help broaden the understanding of staff, people training to work in support or employment services could be encouraged to take student placements with organisations like the National Centre for Independent Living and People First and as personal assistants to disabled people. Both the Independent Living Fund and local authorities could include work and work aspirations in their assessments.

At present personal assistance users are bearing the risks of working

themselves, and carrying the complexity of the different systems, which support them. The government departments involved could undertake further consultation and research, driven by personal assistance users themselves, to identify future improvements to policy and practice.

Remaining charging anomalies

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The Department of Health guidance marks an improvement for working personal assistance users but there are concerns that this may be at the expense of other personal assistance users on low incomes. In theory at least it is possible that the earnings disregard may place pressure on other forms of income which can be charged against, such as occupational pensions and incapacity benefit, often payable to people who are not in work and so with limited opportunity to increase their incomes. People out of work could pay a higher charge than someone in work with earnings. For instance someone receiving Income Support could face charges against the Severe Disability Premium *and* DLA; in employment, charges would be just against DLA if no Housing Benefit is in payment (and so no Severe Disability Premium entitlement in work).

While the Income Support 'buffer' may protect people just above the Income Support threshold, and the disability spending assessment may

protect others who can demonstrate they have significant costs, the latter could favour those with high and verifiable spending patterns rather than people who find it difficult to prove their costs or go without particular items. The combined impact of the new means test is difficult to predict but will need to be monitored to ensure that service users are not penalised financially simply because they have support needs.

At the 'job search' stage of distance from the labour market people could be particularly affected, for instance, losing a job or being off sick could mean people face paying a higher charge for support at the point when their income drops.

One of the issues arising from the work of the group is the lack of hard data about personal assistance users, in particular their work status and aspirations. This needs to be routinely kept by local authorities. The impact of the new charging regimes, especially the unfamiliar territory of including an individual assessment of disability-related spending into the means test, needs to be monitored closely.

Medium- and longer-term changes

From 2003 some other policy changes may have an impact on personal assistance users. This includes the full implementation of Supporting People, the introduction

of the Child Tax Credit and Working Tax Credit (replacing the Disabled Person's Tax Credit), and the pension credit. The new agency for employment and benefits for people of working age, Jobcentre Plus, should also be under way. 2003 could also be the first year of new central government grant to local authorities replacing the standard spending assessment (to be frozen for two years ending 2006/7).

These developments suggest that:

- From 2003, proposed changes to tax credits include the removal of both the tariff income rules and the limits on capital, instead taking actual taxable income into account; this would be an opportunity to further review the impact of savings.
- Better integration of charging systems and procedures between agencies providing support will be needed.
- The introduction of new agencies like Jobcentre Plus and detailed changes like tax credits can potentially become further layers of complexity for personal assistance users, and so their impact on personal assistance users needs to be worked through by the agencies involved.
- Information about the tax credits will need to be disseminated to front-line staff (together with the equipment and confidence to undertake 'better-off' calculations) and users themselves.

- Ensuring that the support needs and work aspirations of working-age disabled people are met could be considered within any funding formula for local authorities with social services responsibilities.

Changes to local government, and possibly regional government could provide opportunities to consider the organisation and role of a single support agency in the longer term (post 2006 or so).

For instance, as well as devolved powers to Wales, Scotland and Northern Ireland, the government is aiming for directly-elected regional government in some regions if people chose this through a referendum (predominantly where there are unitary authorities). Activities at regional level can perform a 'middle ground' function between the local and the national; logically local government could tackle issues where local choice was important (such as waste collection) and regions could function as 'agents' in implementing nationally agreed policies (Richards 1998). International experience indicates that functions of health and social care can be undertaken at regional level (Russell Barter 2002). This opens up the possibility that regional government could commission support services for working-age disabled people (such as now provided by the Independent Living Fund and local authorities), placing support needs within the

context of employment and regeneration.

A review of local government finance to take effect in the longer term could also present opportunities to reconsider the extent and role of funding for support packages from social services authorities.

Appendix I

Membership and terms of reference for the working group

In early 2001, the Joseph Rowntree Foundation, the Disability Rights Commission and the National Centre for Independent Living set up a working group to consider changes in policy and practice to tackle the 'personal assistance trap' faced by working-age disabled people receiving support from their social services department or the Independent Living Fund.

Terms of reference

Focusing on people living in the community (rather than residential care) the working group aimed to:

- Examine the barriers experienced by personal assistance users in entering into and retaining work.
- Explore alternative approaches to help personal assistance users move from welfare to work and to make work more sustainable and financially rewarding.
- Examine, and make recommendations about, the short-term and longer-term policy options, both within and across current departmental boundaries,

having regard to the feasibility and cost of options, and the role of different mechanisms of support.

The working group process

The working group met on four occasions to discuss the problem of the personal assistance trap, including historical assumptions which had influenced policy and practice, and formulated some principles to help inform future policy-making. Some key options were also examined. The working group undertook these discussions through exercises in small groups and pairs as well as more formal discussions on draft papers. Discussions were carried out in accordance with 'Chatham House' rules. A separate consultation exercise was carried out with people with learning difficulties and discussions held with other individuals and groups. Our work was also informed by figures produced by the Centre for Analysis of Social Exclusion at the London School of Economics, based on the 1996/7 Disability Follow-Up to the Family

Resources Survey. However, given the problems of accurately identifying people faced with the personal assistance trap, the data is limited so the figures referred to in this report should be treated as a rough guide rather than definitive estimates.

Membership

The working group included representatives of disability organisations and disabled people caught in the personal assistance trap, local authority social services, academics, as well as officials from different government departments and agencies. Officials were in the role of ‘participant observers’ rather than full members of the working group.

We are grateful to everyone who took part.

Members:

Jane Campbell	Disability Rights Commissioner and chair of group
Marilyn Howard	Policy analyst and secretary to working group
Janet Lewis	Research Director, Joseph Rowntree Foundation
Ruth Bailey	Personal assistance user
Tania Burchardt	Centre for the Analysis of Social Exclusion, London School of Economics

Julie Charles	Equalities
Nick Danagher	BCODP independent living committee
Mike Hurdiss	Scope
Ann Kestenbaum	Independent researcher/Independent Living Fund
Monica Kreel	Disability Rights Commission
Jenny Morris	Independent researcher
Sue Maynard Campbell	Chair, Advisory Committee for Disabled People in Employment and Training
Lorna Reith	Disability Alliance
Mik Standing	Advisory Committee for Disabled People in Employment and Training
Chris Taylor	Hampshire Social Services Department and the Association of Directors of Social Services

Officials attending the working group as observers:

Department of Health
Crispin Acton, Simon Stockton
Independent Living Fund
Elaine Morton
Inland Revenue
Jonathan Langridge

HM Treasury
Beth Russell (to May 2001), Wendy Sleath (from May 2001)

Department for Work and Pensions
Ken Ball, Helen Gahir, Geoff Warriner, Chris Burke (former DfEE), Simon Francis (former DfEE)

The group also received assistance from Tom Sefton (London School of Economics), Paul Gemmill (Disability Rights Commission), Emma Dyer (Hampshire Social Services Department), Jenny Webb (Kingston upon Thames Social Services Department). Readers who commented on papers prepared for the working group included Michael Carpenter (Audit Commission), Paul Newman (Employers Forum on Disability), Patricia Thornton and Anne Corden (Social Policy Research Unit at York University), Helen Barnes (Policy Studies Institute).

Andrew Holman (Community Living) organised and supported the consultation with people with learning difficulties, which adopted a 'select committee' format. 'Witnesses' were Bernadette Shrubshall, Douglas Armstrong (Thera Trust); Yvonne Holman (Community Living). Discussing the issues were John Patrick Woodhouse and Catherine Laird (Cambridge Speaking Up); Raymond Johnston (Lambeth Accord); Mark Conquer, Hilda Turner and Jan Meara (ACE); Janet Brandish, Shaun Beaumont and Maggie Beat (People First Norfolk).

The working group also received advice and information from: the National Centre for Independent Living; the West of England Centre for Independent Living; the Leonard Cheshire Foundation; Hammersmith and Fulham Action on Disability; Equalities; Greenwich Association of Disabled People; Kingston Association of Disabled People; Lothian Centre for Integrated Living; and members of the Let Us Work Campaign.

Appendix II

Estimates of personal assistance users in work or wanting work

Personal assistance users are difficult to identify from available data and local authorities do not routinely keep information about work status.

Independent Living Fund clients in work

However, information from the Independent Living Fund for the working group showed that, in May 2001, 80 recipients were in employment. This was broken down as follows:

Table A1 Numbers of ILF clients in work by age group

Age	1993 Fund	Extension Fund
Under 25	5	1
26-35	14	18
36-45	13	12
46-55	6	5
56+	5	1

Table A2 Numbers of ILF clients in work by impairment category

	1993 Fund	Extension Fund
AIDs related	-	1
Arthritis	4	-
Cerebral palsy	7	5
Cerebro-vascular	2	-
Friedrich's Ataxia	1	1
Learning difficulty	1	-
Motor neurone disease	1	-
Multiple sclerosis	4	2
Muscular dystrophy ¹	10	10
Osteoporosis	1	-
Polio	-	2
Spina bifida	-	1
Spinal injury	11	12
Other	1	3
Totals	43	37

Source: Independent Living Fund information to working group

Note 1: Includes Spinal Muscular Atrophy

Work incentives estimates

In addition the Centre for Analysis of Social Exclusion examined data from the 1996/7 Disability Follow-Up to the Family Resources Survey. Because there is little hard evidence about how personal assistance users might respond to financial incentives or disincentives to work, assumptions were made in the modelling for the working group. The possible 'scenarios' were:

- Scenario 1 – All personal assistance users who would like work find a job. An extreme assumption is that if means testing for charges were removed then most of these would find employment, although this also assumes that the Disability Discrimination Act will be effective in tackling some of the other employment barriers.
- Scenario 2 – Employment rates of personal assistance users rise in line with other disabled people (i.e. double the estimated current rate), based on the assumption that disabled people not receiving personal assistance do not face the same financial disincentives. However, many personal assistance users have impairments which score more highly in the OPCS severity categories, although adjusting for this only reduces the employment rate marginally. This might also be a little optimistic if Scenario 1B (adjusting for those who say they are unable to work) is lower.

- Scenario 3 – The incentive effects of removing charges are comparable with those for other policies with similar aims. Disability Working Allowance evaluation found that few had heard about it (so it could not be an incentive), and of those who had heard of it, the rate of moving into employment was low and not significantly different from those who had not heard of it. Evaluation of other schemes – such as Jobmatch – suggests an impact of five percentage points.

Table A3 Summary of potential incentive effects of removing charges

Scenarios	Employment rates (%)
Current rate	18
<i>Scenario 1</i>	
a) All who want work get a job	40
b) As above, excluding those also saying they can't work	25
<i>Scenario 2</i>	
a) In line with disabled non-personal assistance users	33
b) As above, adjusting for severity	32
<i>Scenario 3</i>	
a) Similar to Disability Working Allowance	18
b) Similar to lone parents (tax credit)	19
c) Similar to Jobmatch	23

Source: Centre for Analysis of Social Exclusion estimates for working group

Table A4 Types of qualifications by employment status

	Working	Available for and seeking work	Not looking for work but wants a job	Not looking for and not wanting work	Totals
PA¹ users					
Degree level	23%	*	3%	5%	9%
A level or higher diploma	40%	*	16%	14%	19%
GCSE or below	18%	*	20%	14%	16%
No qualifications	19%	*	61%	67%	56%
Non- PA users					
Degree level	9%	5%	3%	3%	5%
A level or higher diploma	24%	21%	16%	14%	18%
GCSE or below	29%	36%	21%	18%	23%
No qualifications	39%	38%	60%	65%	54%

Source: Centre for Analysis of Social Exclusion estimates for working group

Note: 1 PA = personal assistance

* = sample size too small

Table A4 shows the qualifications of disabled people who use personal assistance and those who do not by employment status.

Notes

- 1 Department of Health (2001) Community Care Statistics 2000/01. Referrals, Assessments and Packages of Care, report of the first year of the roll out of RAP, December.
- 2 Department of Health (2001) Community Care Statistics 2000/01.
- 3 The Health and Social Services and Social Security Adjudications Act 1983.
- 4 Department of Health (2001), 'Fairer Charging Policies for Home Care and other non-residential Social Services: Guidance for Councils with Social Services Responsibilities'.
- 5 Local Government Association/Association of Directors of Social Services/Society of County Treasurers/Municipal Treasurers (2001) 'Local Authority Social Services Budget Position September 2001'.
- 6 Hampshire – website.
- 7 Department of Health (2001), Community Care Statistics 2001/01. Referrals, Assessments and Packages of Care, report of the first year of the roll out of RAP, December.
- 8 Department of Health (2002) 'Personal Social Services Current Expenditure in England: 2000-2001'. Bulletin 2002/08 March.
- 9 Social Services Inspectorate (2000) 'Inspection of Welfare to Work for Disabled People, Knowsley Metropolitan Borough Council'.
- 10 Department of Health (2001) 'Fair Access to Care Services: General Principles of Assessment for Adult Social Care', Consultation Draft, July.
- 11 Disability Rights Commission (2001) 'Briefing on Disability by Ethnic Origin', February.
- 12 Department of Health (2001) Community Care Statistics 2000/01.
- 13 Department of Health (2001) 'Valuing People: A New Strategy for Learning Disability for the 21st Century', a White Paper, March, Cm 5086.
- 14 Disability Rights Commission (2001) 'Disability Briefing: September 2001'.

- 15 Department of Health (2001) 'Valuing People: A New Strategy for Learning Disability for the 21st Century', a White Paper, March, Cm 5086.
- 16 Information from Independent Living Fund to working group.
- 17 *Community Care Magazine*, 6–12 December 2001.
- 18 Labour Force Survey summer 2001, *Labour Market Trends* December 2001.
- 19 This figure should be treated with caution as this is an estimate from schemes, not all of whom checked with their users directly.
- 20 See, for example, Department for Work and Pensions, 2001, 'Tax Benefit Model Tables', June.
- 21 Department of Health (2002) 'Fairer charging policies for home care and other non-residential social services: practice guidance', February.
- 22 Department of Health (2001) 'The NHS Plan: A Plan for Investment, a Plan for Reform', Cm 4818–1, July.
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