

# The costs and benefits of independent living

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A report of research carried out by SQW on behalf of the Office for Disability Issues, Department for Work and Pensions

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First Published 2007.

ISBN 978 1 84712 200 1

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Printed by Corporate Document Services.

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# Acknowledgements

This report was commissioned by the Office for Disability Issues (ODI). In addition to the authors of the report, the following SQW consultants contributed to the study: Nick Gardner, Helen German, Kate Hills and Lisa McCrindle.

We would like to thank all the members of the ODI project steering group for their advice and contribution to the research. We would also like to express our appreciation to the policy specialists and service providers for their expert input into the project. In addition, we wish to thank the disabled people and their families who agreed to be interviewed about their experiences relating to independent living. Finally, we are grateful to Jenny Morris for her management of the project and support and guidance throughout, and to Fraser Macleod for co-ordinating the project on behalf of the ODI.



# 1 Introduction

- 1.1 The Office for Disability Issues (ODI) commissioned SQW Limited (SQW) to identify and review the costs and benefits of Independent Living (IL) for disabled people. The purpose of this research is to inform the first stage of the Independent Living Review, which is a 12-month project being carried out by the ODI, to develop practical proposals to tackle the barriers to independent living. This analysis will inform the ODI's 'invest to save' proposals to be made to HM Treasury ahead of the Comprehensive Spending Review (CSR) 2007. Although a case for investment can be made on the grounds that it will address the social exclusion that many disabled people experience through the failure of service provision to enable them to live independently, the case can be strengthened if there is evidence for the cost-effectiveness of such support.
- 1.2 The study comprises two essential components. First, is an extensive review of the literature on the potential costs and benefits associated with investment in IL support, as compared to more conventional forms of service provision. This has involved the analysis of around 100 documents, including peer reviewed academic journals, government reports from the UK and comparable foreign countries, grey literature and publications by independent research organisations.

- 1.3 Second, five illustrative case studies of individual circumstances were undertaken in order to investigate different types of IL support in detail and uncover examples of costs and benefits to complement the literature review evidence. The case study scenarios were selected by the ODI IL Review Steering Group. Each involved a series of in-depth face-to-face interviews with service recipients, strategic policy stakeholders and service delivery representatives, as recommended by the Steering Group.
- 1.4 Where available data has permitted, for both the literature review and case studies, costs and benefits for conventional and IL care have been assessed and compared at individual, service delivery and macro-economic (Exchequer) level.

## Structure and summary of the report

- 1.5 Chapter Two opens this report with a brief overview of Independent Living as a policy concept and the relatively recent steps in its UK implementation. In Chapter Three we highlight the main findings of the literature review. Chapter Four contains the five detailed case studies, illustrating individual experiences of conventional and IL support mechanisms. It also includes a wider discussion of the costs and benefits at service delivery and macro-economic level using the information collated during the case study investigations and the strategic consultations.
- 1.6 The final chapter highlights the gaps in available data, identifies some of the barriers to implementation of Independent Living and draws together the findings from the literature review and case studies. The report's conclusions are summarised below:
- 1.7 At an individual level, there is substantial qualitative evidence, from both the literature review and the case study research, suggesting that IL provides significantly more benefits than conventional forms of service provision. Some of the case studies undertaken as part of this research also indicated that IL can also be cost effective for the individual recipients.
- 1.8 At service delivery level, several published evaluations that were

identified in the literature highlighted the reduced costs involved in the delivery of independent living support mechanisms. Consultations and the case studies undertaken reinforced this view, by highlighting the inherent inefficiencies involved in traditional care provision. It was also pointed out, however, that there would be considerable transformational costs involved in rolling out IL more widely. It is largely expected that these upfront costs will be offset in savings, at both service delivery and macro level, in the long term, suggesting, therefore, the need to accept an 'invest to save' approach.

- 1.9 The published material at macro-economic level on the costs and benefits of independent living is relatively sparse. However, the literature does highlight that there are significant costs for the Exchequer in not addressing barriers faced by disabled people. Evidence from the case studies and consultations corroborates and strengthens this view, showing that investment in independent living would result in sizeable long-term cost savings for the Exchequer due to the increase in tax revenues, a reduced state benefits bill and less pressure on health and acute social care services.



## 2 The policy context

- 2.1 Disabled people in Britain today comprise around one in five of the adult population. The latest estimate from the Family Resources Survey (FRS) of the number of disabled adults in Britain is 9.5 million, 21 per cent of the total population<sup>1</sup>.
- 2.2 Disabled people experience disadvantage compared with non-disabled people, across all aspects of society. According to the Labour Force Survey, disabled people are twice as likely as non-disabled people to have no educational qualifications, more likely to be unemployed or economically inactive, and when in employment earn on average 10 per cent less gross hourly pay than non-disabled employees<sup>2</sup>. Additionally, disabled people face barriers in finding suitable housing, using transport, and accessing appropriate health and social care services.

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<sup>1</sup> Latest estimate from the Family Resources Survey 2003/4, cited in the Disability Rights Commission's Disability Briefing, March 2006. The FRS defines a disabled person as someone with a long-standing illness, disability or infirmity, and who has a significant difficulty with day-to-day activities.

<sup>2</sup> LFS Spring 2005 data, cited in DRC, Disability Briefing, March 2006.

## The concept of Independent Living

- 2.3 Independent Living as a policy concept is about supporting disabled people to live their lives as full citizens and have choice and control over the way in which their care is delivered. Over the past 20 years there has been a radical shift from a welfare system, which has treated disabled people as dependent, passive recipients of 'care', towards a growing recognition of the need for a new approach that enables disabled people to assume an active role in determining how their needs are met.
- 2.4 Central to the concept of Independent Living are the principles of choice and control. In 2004, Jane Campbell, former chair of the Social Care Institute for Excellence, and now chair of the Independent Living Expert Panel, provided the following definition:
- "Independent Living" means that disabled people have access to the same life opportunities and the same choices in every day life that their non-disabled brothers and sisters, neighbours and friends take for granted. That includes growing up in their families, being educated in the local neighbourhood school, using the same public transport, getting employment that is in line with their education and skills, having equal access to the same public goods and services. Most importantly, just like everyone else, disabled people need to be in charge of their own lives, need to think and speak for themselves without interference from others.
- 2.5 This concept of Independent Living is based upon a social, rather than medical, model of disability. The social model recognises that people are disabled by barriers – social, economic, and attitudinal – in society, rather than by impairment in itself. Choice and control, therefore, depend on the removal of these external barriers.
- 2.6 However, it is also recognised that the flexibility and control that

Independent Living provides may not suit everyone. For some individuals, the responsibility for finding their own support workers may cause anxiety or difficulties, particularly if they live in areas where there is a shortage of the workers who can provide the type of assistance they require. The implication is, therefore, that support for Independent Living needs to be personalised and tailored to the needs of the individual.

2.7 The Disability Rights Commission is currently supporting a Private Members Bill on Independent Living in the House of Lords. Introduced by Lord Ashley of Stoke, the Disabled Persons (Independent Living) Bill, includes the following principles of Independent Living:

- Disabled persons should be able to exercise choice, freedom and control and enjoy personal dignity and substantive opportunities to participate fully in work, family life, education, public, community and cultural life.
- Disabled persons are the best judge of their own requirements and therefore any practical assistance and associated support allocated to disabled persons following assessment should be based on their own choices, lifestyle preferences and aspirations.

## The growth of support for Independent Living

2.8 The practical application of the principles of Independent Living can be traced back to the late 1970s/early 1980s when Centres for Independent Living (CIL) were established in California and in the UK<sup>3</sup>. These centres were founded to be run and controlled by disabled people themselves, with the intention that expertise around Independent Living issues could be developed using approaches such as peer support and advocacy.

2.9 In 1987, the UK Government introduced the Independent Living

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<sup>3</sup> Evans, J. (2003), The Independent Living Movement in the UK, [www.independentliving.org/docs6/evans2003.html](http://www.independentliving.org/docs6/evans2003.html) provides an overview of the early development.

Fund (ILF), a scheme which was subsequently modified in 1993. The ILF was set up with the aim of providing financial support for disabled people to enable them to choose to live in the community, rather than in residential care. However, as the Prime Minister's Strategy Unit (SU) report, *Improving the Life Chances of Disabled People* report notes, there are limitations and restrictions placed on the funds available from the ILF. People with weekly support costs over a financial threshold are ineligible to apply for an ILF grant, leaving local authorities with the cost of funding their total support needs if they wish to live outside an institutional setting. This results in some people being pressured into residential care due to the cost ceilings imposed by the ILF and social services departments.

- 2.10 A second milestone in the development of Independent Living policy, was the Community Care (Direct Payments) Act 1996. This established the right for disabled people to receive direct payments for personal assistance so that they can arrange their own services, choose the type of support they want, and how they want it to be delivered.
- 2.11 In 2005, the Strategy Unit report, identified a range of ongoing barriers to independent living for adult disabled people, and disabled young people moving into adulthood<sup>4</sup>. These included the following:
- The support currently provided for people with different needs has not been fitted to the individual. Disabled people have been expected to fit into services, rather than services being personalised to promote independence and extend opportunity.
  - There has been unnecessary bureaucracy and fragmentation in the delivery of services to disabled people, often resulting in a failure to adequately to meet their needs.
  - Policies have not been focused on enabling disabled people

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<sup>4</sup> PMSU (2005), *Improving the Life Chances of Disabled People*, Chapter 4.

to be active citizens or to support disabled people to help themselves. This has often created dependency rather than enabling people to participate in their communities, fulfil their family responsibilities or be economically independent.

- 2.12 The report identified the need for a new approach, which “is not just about being able to live in your own home – though that is often part of it for many disabled people. Rather independent living is about providing disabled people with choice, empowerment and freedom”.
- 2.13 To put this approach into practice, the report set out a detailed and wide-ranging set of policy recommendations. It called upon the Department of Health (DH) supported by DWP, DfES and ODPM to work towards a new approach to supporting independent living, which delivers support, equipment and/or adaptations in a way that:
- addresses all aspects of needs for support and/or equipment or adaptations;
  - is personalised according to individual need and circumstances;
  - is underpinned by the principle of listening to disabled people and acknowledging their expertise in how to meet their needs;
  - maximises the choice and control that people have over how their requirements are met;
  - provides people with security and certainty about what level of support is available;
  - wherever possible, minimises the disincentive to seek paid employment or to move from one locality to another;
  - uses existing resources to maximise social inclusion.
- 2.14 To overcome the current fragmentation of budgets to support disabled people - including community care, housing adaptations, independent living advocacy and employment and education support - the report also recommended that different sources of funding should be brought together in the form of individual budgets.

- 2.15 The DH is leading a cross-government programme of pilots of this new approach, called Individual Budgets. These will test out the effectiveness of different ways of allocating funding to individuals to enable them to design their own support and manage their individual budgets. Other Independent Living support initiatives include the In Control pilots in local authorities, and the Partnerships and Older People Pilots, funded by the DH.

## The Independent Living Review

- 2.16 The first step in responding to the SU report was the establishment of the Office for Disability Issues (ODI), which was tasked with leading the development of joint departmental strategy for delivering equality for disabled people. It was agreed that the most effective way of taking forward the recommendations in the SU's report was to undertake a 12 month Independent Living Review.
- 2.17 The IL Review is a wide-ranging project that will develop practical policy proposals to tackle the barriers to independent living encountered by disabled people. This has involved establishing a cross-government project team within the ODI and an Independent Living Expert Panel to act as an external reference group to provide advice and support to the project team.
- 2.18 The first stage of the Review's work has been to produce recommendations for the Comprehensive Spending Review 2007. As part of this, the ODI has been developing 'Invest to save' proposals, based on the principle that giving disabled people more choice and control over the support they require, will not only promote their social inclusion, but will also be cost-effective.

## 3 Literature review

### Purpose of the review

- 3.1 As set out in the Terms of Reference, the aim of the literature review was 'to cover evidence concerning the costs and benefits of giving disabled people more choice and control over the support they require'. The review was to include both published research and grey literature and, where available, emerging findings from evaluations of relevant current initiatives such as the Partnerships and Older People pilots, the In Control project, and the Individual Budgets pilots.
- 3.2 The process of conducting the literature review comprised the following elements: establishing an analytical framework for the review, including defining the key concepts; defining the search terms; identifying the sources for the literature search; deriving a template for reviewing the documents; and analysing of the findings from the literature.
- 3.3 SQW reviewed close to 100 documents including academic articles in peer reviewed journals, government-funded research in the UK and in other countries, and research conducted by independent research organisations.

## Methodology

### The analytical framework

3.4 It was important at the outset of the research that a clear framework was established for the review to ensure a coherent and consistent use of concepts and for the purpose of assessing the literature against the key study objectives.

### Definitions

3.5 Defining the key concepts associated with the study was critical for the review and necessary in order for us to develop search terms (see Annex A) to identify the most relevant written evidence. Moreover, our preliminary literature investigation had indicated that there are varying interpretations of costs and benefits and support and independent living.

3.6 The Terms of Reference stated the following broad definitions to which we adhered in the study:

- Independent Living defined (by the Disability Rights Commission) as 'all disabled people having the same choice, control and freedom as any other citizen – at home, at work and as members of the community. This does not necessarily mean people doing 'everything for themselves' but it does mean that any practical assistance people need should be based on their own choices and aspirations'.
- Choice and control includes people having direct control over how the support they need is delivered, support provided in a way that addresses all aspects of someone's life and needs, low level preventative support provided at levels of need which prevent higher levels of need and/or dependency.
- 'Support' to include assistance provided by others, whether in the form of personal or nursing care, communication or advocacy support, physiotherapy, learning support, 'talking treatments' etc, aids and equipment, adaptations to the physical environment, the accommodation element in residential or nursing care placements, housing related support.
- Costs and benefits include the cost of support, welfare benefits and taxes, social inclusion and exclusion.

## Costs and benefits typology

3.7 In the typology of costs and benefits that we developed to serve as a guide in gathering and analysing evidence (set out below in Tables 3.1 and 3.2), we deliberately made a distinction between costs and benefits that accrue to the individual, those that are incurred at service provision or delivery level and those that affect the exchequer at a macro level.

**Table 3.1** Typology of costs and benefits of current system (various sources)

Cost	Benefit
<b>Individual level</b>	<b>Individual level</b>
Costs borne by individuals themselves as a result of lack of support	Increased participation (or ability to participate) in the labour market – employment and economic activity
Costs borne by close family members due to provision of informal support, including loss of income and pension entitlements	Increased/additional earnings from employment
Increased dependency on public services	Improved physical and/or mental health
May have a detrimental effect on health	Alleviation of risk
Opportunity costs:	Not having to manage own personal assistance
Non-participation in the labour market	Regulated service provision
Reduced or lack of earnings due to non-participation	
Continued barriers to social participation	
Increased levels of dissatisfaction with quality of life indicators – access to services, participation in social activities, reduced flexibility etc	

Continued

**Table 3.1** Continued

Cost	Benefit
<p><b>Service delivery level</b></p> <p>Time spent on professional assessment and care management</p> <p>Waste resulting from pre-purchasing of services that do not meet individual needs</p> <p>Steep rise in aggregate social care spending</p> <p>Rise in levels of dissatisfaction from those who manage the system</p> <p><b>Macro level (Exchequer)</b></p> <p>Continued welfare benefits</p> <p>Foregone tax revenues from disabled people, and family members providing 'informal' care due to current trends in economic activity</p> <p>Rising expenditure on health and social care</p> <p>Duplication of resources – e.g. on health and social services</p> <p>Worsened social exclusion indicators over the longer term and possible impact on other government interventions</p> <p>Future costs and demand for care adjusted for demographic effects (ageing population)</p>	<p><b>Service delivery level</b></p> <p>Economies of scale</p> <p>Confidence in professional levels of service delivery</p> <p>Protection from risk</p> <p><b>Macro level (Exchequer)</b></p> <p>Savings from unpaid care providers</p> <p>Economies of scale</p> <p>Control over resources</p>
<p>Source: Garb (2003), Robbins (2006), Prime Ministers Strategy Unit (2005), Palmer et al (2005).</p>	

**Table 3.2** Typology of costs and benefits of investment in independent living (various sources)

Cost	Benefit
<p><b>Individual level</b></p> <p>Responsibility for managing own personal assistance</p> <p>Process of adjustment to the new system</p> <p>Personal investment (of time and money) in developing own skills to self direct support</p> <p>Personal investment (of time and money) in developing own skills and expertise to engage with mainstream/community agencies</p> <p>Personal investment (of time and money) in managing own budget/expenditure, including providing accounts</p> <p>Opportunity costs of under or non-investment:</p> <p>Continued barriers to social participation</p> <p>Increased levels of dissatisfaction with quality of life indicators – access to services, participation in social activities, reduced flexibility etc</p>	<p><b>Individual level</b></p> <p>Increased participation (or ability to participate) in the labour market – employment and economic activity</p> <p>Increased/additional earnings from employment</p> <p>Increased access to services including physical infrastructure e.g. transport</p> <p>Increased reported levels of satisfaction with public services</p> <p>Increased ability to obtain most appropriate/personalised type of services which may lead to rising levels of satisfaction with public services</p> <p>Increased levels of confidence in leading an independent life</p> <p>Increased access to 'independent living' options</p> <p>Increased participation in social and cultural activities and improved social networks</p> <p>Other indicators – increased flexibility, choice and control over living, improved quality of life</p> <p>Reduced dependency on informal/family support</p> <p>Increased engagement with service providers</p> <p>Increased development of personal skills</p>
<p>Table 3.2    Continued</p>	<p>Continued</p> <p>Improved physical and/or mental health</p>

Cost	Benefit
<b>Service delivery level</b>	
Cost of providing alternative models/funding mechanisms	<b>Service delivery level</b>
Cost of support – resource inputs (start up costs, staff salary and other administrative and overhead costs); actual costs of delivery of the assistance package; training costs of Personal Assistants; recruitment costs, arranging for emergency cover, non-resource or intangible inputs such as social environments, relationship between workers and users	Benefits of providing alternative models/funding mechanisms
Other hidden costs – liaison between different service delivery partners, short-term costs of hiring extra workers, cost of risk-aversion, time and expertise required to promote development of more appropriate responses to need than currently exist, time and expertise required to seek out mainstream/ community responses to need	Reduced reliance on health and social care workers over time
Continuity in other costs of provision of community support in the short-term	Reduced recruitment and retention costs
	Increased development of wider skills sets for workers
	Reduced information costs due to streamlined processes across agencies
	Improved leadership and ownership of support among workers
	Personalised responses to individual needs may reduce need for more costly residential or home-based services
	Increase in one-off costs of equipment offset by reduction in need for more labour intensive services
	Continued

Table 3.2 Continued

Cost	Benefit
<b>Macro level (Exchequer)</b>	

Continued welfare benefits

Foregone tax revenues from disabled people, and family members providing 'informal' care due to current trends in economic activity

Rising expenditure on health and social care

Duplication of resources – e.g. on health and social services

Worsened social exclusion indicators over the longer term and possible impact on other government interventions

Future costs and demand for care adjusted for demographic effects (ageing population)

### Macro level (Exchequer)

Revenue transfers due to savings on social security benefits

Generation of additional revenue due to increased economic activity

Cost savings/reduced expenditure due to reduced reliance on social care assistance

Potential reduction in demand for health and social care, especially long-term care

Sustainability of preferred support arrangements

### Literature search

3.8 Annex A lists the search terms, derived from the definitions of the key independent living issues, which we employed to identify relevant literature for review. We interrogated a vast range of sources (listed fully in Annex B), including peer reviewed journals, government funded research in the UK and in other countries, and papers produced by independent research organisations.

3.9 Through this process we identified close to 200 articles, documents and reports. From this, it was necessary to derive a 'core list' for the review, identifying only those of most relevance to the study: i.e. those addressing the issue of costs and benefits and those that contained either quantitative or qualitative data. In order to do this, we agreed a set of quality criteria to prioritise the literature. This refinement also enabled us to identify documents contributing to the wider policy context and those that would aid in a discussion of methodologies. This exercise narrowed our initial list to a core list of 110 documents for review, which was approved by the client.

3.10 Tables 3.3 and 3.4 show the characteristics of the literature that was included in the review:

### Table 3.3 Literature review by source

Literature source	No. of documents reviewed
Academic	40
Grey Literature	1
Independent	7
International Organisations	3
Other	1
Plenary Presentation	1
Research Institute	43
UK Government Publication	13
USA Government Research	1
<b>Total</b>	<b>110</b>

Source: Various.

Table 3.4 Literature review by origin

Literature origin	No. of documents reviewed
Australia	5
Canada	1
EU	4
Ireland	1
Norway	1
OECD	1
Sweden	1
UK	85
USA	11
<b>Total</b>	<b>110</b>

Source: Various.

### The review template

3.11 Having selected the documents for review, we developed a template based on the analytical framework (see Annex C), which had the following sub-headings:

- Aims/objectives of the paper in question.

- Definitions of key concepts.
- Policy area in discussion.
- Specific to disability or client type.
- Key findings.
- Methodologies deployed.
- Our own evaluation of the robustness of the findings.

## Literature review findings

### Definitions of Independent Living

3.12 Independent living, as a research topic, is a relatively new concept, despite the fact that the independent living movement and associated programmes have been evolving for many years and have been in existence in the USA and Australia since the 1980s. Our review of the evidence suggests that there are varying definitions of what independent living, choice and control means. However, these definitions do all refer to similar concepts to those suggested by the Disability Rights Commission:

“all disabled people having the same choice, control and freedom as any other citizen – at home, at work and as members of the community. This does not necessarily mean people ‘doing everything for themselves’, but it does mean that any practical assistance people need should be based on their own choices and aspirations.”

3.13 Table 3.5 provides some examples of definitions of independent living found in the literature search.

### Table 3.5 Independent Living definitions

- Fruin (2000), ‘the concept of empowering disabled people to control their own lives as far as possible and to have the freedom to participate fully in the community. It is not the name of a particular service or provision but should be the objective of

services and provision’.

- Kestenbaum (1999), ‘means much more than just getting personal assistance. To achieve Independent Living, disabled people need appropriate housing, personal assistance, transport, access to their environment, advocacy and training, information and counselling, and equipment or technical assistance’.
- Harris (2000), ‘empowerment is the process by which individuals, groups and/or communities become able to take control of their circumstances and achieve goals, thereby being able to work towards maximising the quality of their lives’.
- Miller et al (2006), ‘refers to all disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean disabled people ‘doing everything for themselves’ but it does mean that any practical assistance people need should be based on their own choices and aspirations’.
- DeLong (1985), ‘Control over one’s life based on the choice of acceptable options that minimise reliance on others in making decisions and in performing everyday activities, including managing one’s affairs, participating in day to day life in the community, fulfilling a range of social roles, making decisions that lead to self determination and minimising physical or psychological dependence on others’.

### Independent Living Support mechanisms

3.14 The literature uncovered a variety of mechanisms that deliver the objectives of Independent Living, such as personal assistance, consumer-directed care, home care, person centred planning, Direct Payments and Individual Budgets. Table 3.6 highlights the ways in which these terms are defined by practitioners and researchers.

Table 3.6 Definitions of Independent Living mechanisms

Mechanism	Author	Definition
Consumer Direction	OECD (2005); Wiener (2000)	Arrangements where the individual needing care or their families act as employers of

fire,		care assistants and are therefore able to hire and schedule and supervise the provision of care.
Personal Centred Planning	Sanderson et al (1997) Robertson et al (2005)	A way of helping people who want to make some changes in their life. It is an empowering approach to help people plan their future and organise the supports and services they need. Activities that are based upon what is important to the individual from their own perspective and which contribute to their full inclusion in society.
Personal Assistance is someone everyday	Howard (2003) Doty et el (1996)	Support, delivered through services or payments, that necessary to enable to undertake tasks of living.
provided of with live assistive		A range of human and mechanical assistance to persons with disabilities any age who require help routine activities of daily (ADLs). It can include technologies, home modifications, psychosocial rehabilitation and a range other services. The is provided by an individual who is a personal assistant, aide or attendant.
of core service		

Continued

Table 3.6 Continued

Mechanism	Author	Definition
Direct Payments	Wanless Review (2006)	Offering people the option of receiving a cash payment in lieu of community-based social services so that they choose,

own  
used to  
or  
ices

the

manage and pay for their social care. They can be pay for Personal Assistants to purchase goods or services and also for informal care when carers do not live in same household as the disabled person.

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### Availability of evidence

- 3.15 Evaluating the effectiveness of interventions targeted at disabled people has gathered momentum in the last two decades, as evidence has grown on the significant economic, social and other barriers that disabled people face in their daily lives, compared to non-disabled people. Similarly, the evidence and advocacy of Independent Living appears to have grown significantly. A wide range of literature discusses the rationale for programmes and mechanisms that deliver IL objectives and the potential benefits it can offer to both disabled and older people (Kestenbaum, 1996, Sanderson et al. 1997).
- 3.16 The empirical evidence has often tended to examine the efficacy of specific mechanisms that are intended to deliver IL outcomes, comparing these with support delivered through institutional settings and other traditional programmes of support, such as Medicaid in the United States<sup>5</sup>. In the UK itself, several evaluations of support for disabled people in the current scenario as well as in the IL scenario have been conducted albeit, however, not always incorporating a discussion of costs and benefits. For example, there have been several reports on the Direct Payments scheme for disabled people (Glendenning et al 2000, Boyce and Stainton 2004). A rare recent example of a study in which comparisons have been made between costs under the different support mechanisms is an article by Teresa Poole on Direct Payments for Older People that appeared as an Appendix to the Wanless Social Care Review (Poole, 2006).

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<sup>5</sup> Medicaid is a state administered programme that pays for medical care and services for eligible individuals and families. The payments are not made directly to the recipients but to the health care providers.

- 3.17 Our review suggests that the literature has tended to address the costs of care relatively more than the benefits. This is not surprising due to the notorious difficulties of valuing benefits, especially when they relate to improvements in the quality of life and physical and mental health and well-being. There are, however, ongoing efforts to test out approaches that attribute monetary values to these qualitative aspects (Burge et al, 2006) and to address the methodological issues of valuing benefits and outcomes from social care programmes (Netten et al, 2006).
- 3.18 In addition, the availability of data varied according to the type of costs. Data on the costs of specific aspects of care, for example, informal care, cost variations by setting and types of assistance were extensive, especially at the individual level (Tibble, 2005; Smith, 2004; Burchardt and Zaidi, 2003). However, evidence on the opportunity costs of support associated with IL was relatively sparse.
- 3.19 There is little evidence on macro level costs and benefits of different types of support for disabled people in the literature. Although large-scale initiatives, such as the New Deal for Disabled People in the UK and Medicaid in the USA, have been evaluated, these studies have mostly looked at the outcomes for individuals and service providers. The lack of macro level evidence could be partly attributed to the argument put forward by economists that disability benefits are transfer payments and hence redistributive costs, rather than seeing them as an investment that may result in some measurable economic benefits.
- 3.20 Finally, even where financial and non-financial data on costs and benefits are available, there needs to be careful assessment of the methodologies deployed to arrive at these estimates. Much of the academic literature has focused on evaluating the impact of aspects of traditional support mechanisms, deploying robust methods for estimating costs and benefits, including the use of panel data and large-scale surveys and econometric and statistical modelling techniques.

3.21 However, owing to the relatively new interest of the research community in IL, there is relatively less research that deploys similar methods to evaluate the costs and benefits of delivering alternative forms of support. As some of the independent living support programmes are relatively small scale pilot projects with, to date, little emerging evidence on costs and benefits, this finding is not entirely surprising.

### The nature and extent of barriers for disabled people

3.22 The literature review uncovered considerable detail on the nature and extent of barriers faced by disabled people, hence highlighting some of the rationale behind the IL movement.

3.23 There is more than ample evidence to suggest a strong relationship between disability and economic and social disadvantage. Disabled individuals are significantly more likely than non-disabled people to be unemployed and economically inactive (Thornton, 2005 and Rigg, 2005). Rigg (2005) found that the median annual growth in earnings was 1.4% lower for disabled men and 0.6% lower for disabled women compared to their non-disabled counterparts. Disabled people were also three times more likely to exit work than non-disabled individuals, the difference being most significant between those whom the study defines as 'more-severely disabled' people, and non-disabled people.

3.24 There are also dynamic, long-term effects on earnings due to disability. A recent American study (Charles, 2003) found that disabled men experience sharp drops in earnings soon after the onset of disability. Even though much of the immediate reduction is compensated for in the following years, there are significant long-term losses in expected annual earnings, approximated at 12% per annum.

3.25 Economic disadvantage also increases when coupled with other individual characteristics associated with economic exclusion. Charles (2003) found that being older, non-white, more chronically disabled and less educated increased the level of earnings lost and made recovery more difficult over time.

3.26 Burchardt (2003) reviewed existing evidence and analysed the British Household Panel Survey data to explore the relationship between social exclusion and the onset of an impairment. Her research complemented Charles' 2003 study, as it found that

those with a sudden onset of an impairment were more likely to be on a falling income trajectory than those whose conditions developed gradually. She argued that there was a continuing need for benefits that protect against income shocks as a result of the sudden onset of disability.

- 3.27 Disabled people are also more likely to face barriers such as discrimination at work and elsewhere and social exclusion. Miller et al (2006) catalogue the ways in which society discriminates against disabled people and prevents them from living their lives the way they would like to. Thornton (2005) quoted several econometric studies that found unexplained differences in earnings and employment rates, which could not be attributed to personal or job characteristics and that could be due to discrimination, which is generally hard to measure.
- 3.28 The Social Exclusion Unit Report on Mental Health and Social Exclusion (2004) identified a range of significant barriers for those with mental health support needs, including difficulties in accessing employment opportunities, and a lack of suitable social networks and leisure activities.
- 3.29 Emerson et al (2005) conducted a national survey of adults with learning disabilities in England and found that these individuals were often socially excluded, had little control over their lives and had very few opportunities to be independent.
- 3.30 Our review also suggests that besides labour market and social disadvantage, disabled people are often inappropriately targeted by government policy. The 2005 report for the Prime Minister's Strategy Unit<sup>6</sup> highlighted two significant barriers that affect all aspects of disabled people's lives including where they live, their personal relationships, educational and employment opportunities, access to healthcare, access to leisure activities and participation in community:
  - The support which society provides to disabled people is

generally not appropriate or fitted to the person, including service provision that is unduly bureaucratic and fragmented across delivery agencies.

- Policies and practices do not pay enough attention to enabling disabled people to be active citizens.

3.31 Simons (1998) identified specific barriers facing people with learning disabilities:

- Specialist services are often patchy and poorly run and regulated and fail to encourage self-determination.
- There are perverse financial incentives in favour of residential care that prevent people from accessing other housing and support options.
- There is restricted growth of supported employment due to reliance on social care and continuing education provision that is not often suited for those outside college.

3.32 A study by Bignall and Jabeer (2000) found that policies are often focused on barriers specific to impairment and do not address the simple issue of whether disabled people have enough to secure a standard of living that is comparable to that of non-disabled people.

### The review of costs and benefits

3.33 As outlined earlier on in this chapter, the typology we developed to analyse the literature distinguished between costs and benefits that accrue to the individual, those incurred at service provision level, and the macro effects at exchequer level. Our findings from the literature review are discussed below within the scope of this distinction.

### At individual level

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<sup>6</sup> PMSU (2005), 'Improving the life chances of disabled people in the UK today'.

### Conventional support services

- 3.34 There is a substantial body of evidence that suggests that the extra costs of disability to individuals are substantial and significant. Burchardt and Zaidi (2003) applied a standard of living approach and used multivariate modelling to analyse the relationship between living standards, income and other attributes among disabled people. They used data from the Family Resources Survey (FRS) and the British Household Panel Survey (BHPS) and found that the extra costs of disability are substantial and could consume between 11 and 69% of income, especially for those living alone. Costs are also likely to rise with the severity of disability. Extra costs for a household with mean income ranged from £113 to £551 per week.
- 3.35 Similarly, Smith et al (2004) adopted a budget standards approach to estimate disabled people's cost of living. This approach is based on the premise that in order for society to agree an acceptable standard of living there needs to be a consensus about what constitutes minimum needs. The method involves asking people to list items that they considered to be essential to maintain a minimum standard of living. The authors collected and analysed data on capital costs, weekly expenditure and personal assistance costs. Disabled people were categorised as those with low-medium needs, medium-high needs, intermittent needs, those with hearing impairments and those with visual impairments.
- 3.36 The authors found that while total costs ranged from £1513 per week for those with high-medium needs to £389 per week for those with low-medium needs, personal assistance costs could contribute significantly to total costs, ranging from 11 per cent to 72 per cent of the total. They were estimated at £980 per week for those with high-medium needs and £960 per week for those with hearing impairments. The study highlighted that the costs of living for a disabled person vary according to whether they have high or low support need, but that personal assistance costs are considerable regardless.
- 3.37 There is evidence of wider costs to the family too. Altman et al

(1999) used large survey data in the USA to model the impact of having a disabled family member on healthcare utilisation and healthcare expenditure, and found that the mean expenditure for families with disabled members was substantially higher than those without.

- 3.38 There is wide acknowledgement of the need to account for the contribution of informal care in providing support to disabled people and to quantify the associated costs (Glendinning et al, 2006 and Lundsgaard, 2005).
- 3.39 In 1998, a large scale study of the costs and benefits of providing informal care to older people, identified as 'mentally or physically frail' and living in private households, was carried out as part of the Resource Implications Study of frail older people (Bamford et al., 1998). Of the 1444 sample, 884 nominated their informal supporters for participation in the study; formal caregivers and paid supporters were excluded. Overall, the vast majority (95 per cent) identified positive aspects of their role. This study provided detailed data on the financial, opportunity and social costs incurred by informal carers. Including travelling and other expenses. Nearly half (43 per cent) reported financial costs associated with care giving (estimated as £3 median weekly expenditure). Around a quarter reported an impact on employment, resulting in altering working arrangements or changing or reducing their hours. One in five reported that they had given up employment to support the individual. Supporters of subjects with both mental and physical support needs reported higher costs. Nearly half the respondents reported at least one restriction related to social activities or community participation. Note that no values were attached to time costs and costs due to reduced or changed working patterns. A key finding was that daughters reported incurring more financial, opportunity and social costs than other care givers.

### Independent Living support

- 3.40 Against the backdrop of the costs incurred by individuals under traditional levels of support, there is a growing body of research focused on analysing the costs and benefits to an individual, of independent living support options. A good early example is a US study by Prince et al (1995), which comprised a survey of a small sample of individuals. The authors developed several indices to

measure quality of life indicators such as perceived health status, satisfaction, participation in society, personal assistance satisfaction and personal independence. They found that the self-managed group scored significantly higher than the group in receipt of agency provision group in terms of health outcomes, perceived health status, greater satisfaction and greater control over their lives. The authors concluded that there is value in offering users choice and control; those individuals who had experienced it reported high levels of satisfaction, whilst those who had not expressed a desire for choice and control.

- 3.41 Crucially, the self-managed group also appeared to spend significantly less on care compared to the agency provided groups. The mean daily cost of agency provision was \$151, the cost for the self managed group was \$129. When the value of unpaid care that each group reported was taken into account, the differences increased; \$209 per day for the agency provided care group compared to \$161 for the self managed group.
- 3.42 There is also growing evidence on the economic costs and benefits of specific tools that are aimed at delivering independent living objectives, such as the Direct Payments Scheme. As early as 1994, Nadash and Zarb found that these support arrangements were able to offer disabled people a greater degree of choice and control and, consequently, lead to higher levels of user satisfaction.
- 3.43 A report by Clark et al (2004) examined the way Direct Payments work for older people by interviewing a small sample of individuals in three English local authorities. Although no hard data on benefits were gathered, older people receiving direct payments reported 'feeling happier, more motivated and with an improved quality of life'. There was a positive impact upon their social, emotional and physical health. In some cases, they were able to employ Personal Assistants of their choice. Similar results were observed by Boyce and Stainton (2004) in a two year evaluation of Direct Payment Schemes in Wales, where participants identified increased control over their lives, improved self esteem and a range of interpersonal and lifestyle opportunities.

- 3.44 A relatively new approach, Person Centred Planning (PCP)<sup>7</sup> has been developing in recent years as a result of a trend toward individualisation and personalisation in the design of services and supports for people with learning disabilities. Robertson et al (2005) conducted an in-depth study based on 25 individuals in four localities in England who had participated in PCP over a two year period. The study found that PCP led to positive changes for individuals in terms of the size of their social networks, their circle of friends, their presence in the community and the extent and range of their daytime activities. It is worth noting the methodological issues around this study. The two-year time-span over which the study was undertaken was only sufficient to evaluate the short and (to an extent) medium-term impact of PCP. This is problematic given the difficulties known to be associated with attaining certain key outcomes (e.g., inclusive social relationships, paid employment) in the short-term.
- 3.45 There is some evidence to suggest that even when relying on independent living support, service users could be faced with financial disincentives, which may have implications for their economic outcomes. Cava and Kestenbaum et al (1998) conducted interviews with 42 people who needed significant amounts of personal assistance, relying either on Independent Living Funds or their local authorities for funding support. The study found that personal assistance users who wanted to work could do so, with the right sort of assistance, and would prefer to have direct payments rather than services from local authorities, due to the flexibility that this afforded them. However, the application of means testing to the provision of community care and personal assistance meant that there could be significant financial disin-

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<sup>7</sup> "When we use the term "person centred", we mean activities which are based upon what is important to a person from their own perspective and which contribute to their full inclusion in society. Person centred planning discovers and acts on what is important to a person. Person centred approaches design and deliver services and supports based on what is important to a person. Hence person centred planning can promote person centred approaches" (Department of Health, 2001, Valuing People: A New Strategy for Learning Disability for the 21st Century).

centives for those who wanted to work. Hence, an important consideration from the policy perspective would be to ensure that means testing takes account of any disincentives and associated opportunity costs arising from entering employment.

### At service delivery level

- 3.46 The evidence on costs and benefits of IL at service provision level is relatively rich and varied. Our review found that the key drivers of costs (and benefits to some extent) at service delivery level were types of settings, types of care, types of impairment and extent of severity.
- 3.47 Much of the general literature that is focused on service provision for disabled people has tended to involve economic analysis of the costs of settings or accommodation arrangements for different client groups, mostly those with learning disabilities, albeit with mixed results. For example, Schneider et al (2003) examined cost variations according to the living arrangements of 132 people in South London with dementia by level of dependency, at three points in time (referred to as Time 1, 2 and 3), between 1997 and 1999. The data was analysed according to the living arrangements of each person with dementia – alone, with a carer, community based ‘domestic living’ such as sheltered housing, and non domestic care, which is defined as accommodation in residential and nursing homes. The predictors of costs were identified using multivariate analysis where the independent variables used were informal care, disability and place of residence.
- 3.48 The strongest cost differences found were between people in non domestic and community settings at ‘Time 1’, but these were not found later in the study, suggesting that the differences were not significant over time. People living alone had lower costs for medication, outpatient and primary care and for NHS services overall. They had slightly higher costs for community health care and this was marginally statistically significant. The overall use of formal services did not differ between the two groups (co-resident carers and those living alone) at any point in time.
- 3.49 Non-domestic care appeared to have a negative influence on the costs of both formal and informal care. The study overall showed that even after using very conservative estimates of costs, informal care was a significant element of the total costs of care.

- 3.50 Another study by Knapp et al (2005) investigated the links between the degree of intellectual disability, challenging behaviour, service utilisation and cost for those living in care accommodation in England. It used a cross-sectional survey of people with intellectual disabilities, identified via provider organisations, supplemented by the collection of cost data. A multivariate analysis of cost variations was then carried out. In estimating long run marginal opportunity costs for service per day/per hour, the authors found large differences between types of care settings, i.e. whether accommodation was provided by the NHS or the private/voluntary sector. The average total weekly cost for sample members was £692; the largest contributor to overall unit cost was accommodation (85% of total) which included living expenses and staff employed on site - £588 per week. Costs tended to be higher in NHS compared to other settings. One possible explanation for this finding is the increased likelihood of NHS settings catering for severely disabled people and having higher staff/resident ratios. Costs varied significantly between individuals and although the costs tended to be higher for those with a more severe disability, the costs were more likely to be influenced by the sector and size of accommodation.
- 3.51 Several evaluations of tools and mechanisms designed to deliver independent living have been undertaken in recent years. These have mostly involved relatively small samples of individuals and service providers, which is unsurprisingly, as many of the support options are pilots and at early stages of implementation. Hence, although the robustness of the methods can be questionable, they provide valuable early insights on the issues around the associated costs and benefits at service delivery level.

### Direct Payments

- 3.52 A very early study by Nadash and Zarb (1994) interviewed 70 disabled individuals from four local authorities and used detailed budget data supplemented by a national postal survey of all authorities in England, Scotland and Wales to calculate costs of delivery of Direct Payments compared to conventional services.

Also assessed was current availability of payment schemes and the extent of support for payments among local authorities.

- 3.53 The study found that support arrangements financed by direct/indirect payments were, on average, between 30% and 40% cheaper than equivalent service based support. The average hourly unit cost of support for people receiving payments was £5.18 compared to £8.52 for service users. Part of this difference was related to the fact that payments from the Independent Living Fund tended to be typically cheaper than payments made under schemes operated by local authorities. The authors attributed the difference between the costs of direct/indirect payments and service provision on the administrative overheads involved, which can be considerably higher for conventional service based support.
- 3.54 The study also found that support arrangements that were funded through the payments option were almost invariably more reliable (and, therefore, more efficient) than those supported by direct service provision. They were able to meet a wider range of personal assistance needs.
- 3.55 The Wanless Review on support for Older People (Wanless, 2006) contains an appendix examining the cost effectiveness of the Direct Payments system. The earlier study by Nadash and Zarb (1994) had estimated that support arrangements for disabled adults (mostly under 65 years old) funded by direct/indirect payments. The author of the Wanless assessment, Teresa Poole, suggested that direct payments were between 20-25 per cent cheaper than equivalent services for older people, a finding which points to the cost effectiveness of direct payments. However, she also noted that there are methodological difficulties comparing costs because, for example, personal assistants hired directly by users may not receive paid pensions or sickness benefits.
- 3.56 An example of actual costs provided by Poole comes from a report by the London Borough of Richmond upon Thames in March 2005. This report examined the costs of its Direct Payment Scheme for

recipients of all ages. Based on the local authority's own assessment, its costs were estimated at £12.21 per hour (excluding council administrative costs) for agency home care provision, compared to £10.14 per hour under Direct Payments. Overall, Direct Payments were estimated to reduce costs by around 17% of the conventional service costs. Moreover, the local authority's report pointed out that the agency home care fees were set to rise to £12.95 an hour, which would raise the borough's overall savings from Direct Payments to an estimated 23 per cent.

3.57 However, there could be potential costs of delivering independent living options that may not always be accounted for. A recent review of support options for disabled individuals who require a high level of assistance (Kestenbaum, 1999) analysed the cost and other implications of the Independent Living Fund<sup>8</sup> through consultations with stakeholder and delivery organisations, analysis of administrative data and applications to the fund, and focus groups/discussion days with visiting social workers and contact officers dealing with disabled people with high support needs. There were wide discrepancies between the outcomes for disabled people, depending on where they lived and when their support packages were first set up. The author argued that the potential higher costs of delivering independent living support could be related to several factors, including the following:

- Living alone with little or no informal care having moved from institutional care into a specially adapted property, or because the person who was previously their informal carer has died or left them (spouse or partner).
- They have lived alone for some time, but their condition is worsening, although not suited to institutional support.
- Living in a family situation with another person who is unable to provide sufficient support.
- Live-in care is not appropriate, so a more complicated, higher cost system needs to be in place where support is available

<sup>8</sup> The Independent Living Fund is a government funded discretionary trust that provides financial help to severely disabled people so that they can buy personal and domestic assistance in the community rather than live in community care.

- Rural isolation, which pushes up travel costs.
  - Specialist/highly trained assistants are needed to cope with a rare or highly dependent situation.
  - The disabled person's impairment means that they require a very clean/disinfected environment.
  - 24-hour supervision is needed due to behavioural or medical problems but it is not desirable or suitable for institutionalisation.
- 3.58 There will also be other costs associated with the diversion of resources from non-independent living based services and the increased administrative and legislative time needed to make decisions and costing estimates.
- 3.59 The Wanless Review also highlights one of the implicit costs to the users of Direct Payments: in return for greater choice and control, the burden of administration tends to fall on users and their families. The Review identifies a number of barriers to the take up of Direct Payments, including a lack of administration support for older people to help them employ a care worker. It acknowledges that further research is required to understand more fully how Direct Payments money is spent, but concludes that there is evidence that many people want choice in how their services are provided and the flexibility that it affords them.
- 3.60 Glendinning et al (2000) also discussed the issues and practicalities around the experience of Direct Payments, acknowledging the potential benefits of being able to devise individualised, flexible and responsive packages of assistance and greater level of independence coupled with a higher quality of life. The authors suggest delivering these goals via a closer integration of health and social care services.

### Person centred planning

- 3.61 An evaluation of costs and benefits of Person Centred Planning (PCP) for people with learning disabilities also indicated that mechanisms of independent living can indeed be cost effective, but noted that the potential benefits may not be measurable in the short to medium term. Robertson et al (2005) evaluated PCP by following the first 25 people at each of four localities (a large rural area, two metropolitan boroughs in Northern England, and

one inner London borough) who participated in the PCP process over a two year period. The costs associated with developing and implementing PCP and the costs of support for each individual were recorded. The evaluation also included manager and practitioner interviews.

- 3.62 Overall, the authors observed a non-statistically significant growth in the average weekly cost of the service package per participant of around 2%: from £1326 prior to implementation, to £1356 post implementation. Accommodation costs comprised around 88% of the costs. The findings suggested that PCP did not lead to significant cost increases in service packages. However, although the evaluation reported several important benefits to individuals who had participated in the programme, it also argued that the two year time span of the study was insufficient to measure the longer term impacts of PCP, particularly with regards to key outcomes such as paid employment and inclusive social relationships.

### Other Independent Living Mechanisms

- 3.63 Some support mechanisms such as Individual Budgets and the In Control project are in very early stages and findings from ongoing evaluations are indicative only. Duffy (2005) discussed the efficacy of resource allocation for care under the traditional system, and suggested ways in which greater cost effectiveness and better care could be achieved in local authorities where Individual Budgets are being piloted. Duffy asserted that the prevalent resource allocation system (RAS) has a number of perverse consequences and a big challenge is to ensure that an individual budget is not merely treated as a bureaucratic solution to problems in the delivery of social care system and that it is used to genuinely empower disabled people. This will then result in significant benefits. The In Control programme is seeking to develop a model of service delivery that promotes self-directed support. The underlying principles of the programme include systems of representation of disabled service users, supported decision-making, and an approach to planning that promotes genuine flexibility in how resources can be used, and freedom from bureaucracy.

## Benefits

- 3.64 From the perspective of service provision, the evidence on benefits is sparse as such. Nadash and Zarb (1994) had surveyed all local authorities in England, Wales and Scotland and found considerable support for payments for personal assistance. The best run schemes involved ongoing support and advice either from a dedicated independent living scheme worker employed by social services, or a local disability organisation contracted to provide this service on behalf of the local authority.
- 3.65 Tilly et al (2000) analysed the development, design and experience of consumer directed home care programmes in Austria, Germany, France, the Netherlands and the United States, and reported some evidence that individual workers had fewer clients compared to agency workers, and hence could have better relationships with beneficiaries. They appeared to fare better than agency workers in their work environment, even when they received less by way of fringe benefits and other financial perks.
- 3.66 Our stakeholder consultations suggested that while there is little evidence to suggest that independent living options can deliver their objectives within comparable costs of traditional support, they believed that using conventional services creatively (like PCP) could deliver cost effective solutions and could be tailored for specific types of disabled people such as older people and those with learning disabilities. They reiterated the point that has been raised by Tilly et al (2000) that older people are less likely to want consumer direction than younger persons, and would prefer a choice of models to suit their needs. This raises questions about the capacity of older people to manage their own care.

## At macro level

- 3.67 Our review indicated that there is little evidence to suggest whether independent living support options offer net benefits to the exchequer, over time and when compared to traditional support mechanisms.
- 3.68 A few studies have sought to provide estimates of the economic costs to society of not addressing the barriers that disabled people face. Much of the focus is on the costs arising from the loss

of output from people with mental health support needs who are unable to participate in the labour market. For example, a report by the Centre for Economic Performance's Mental Health Policy Group on depression and chronic anxiety (2006) quoted an earlier estimate from the Sainsbury Centre for Mental Health (2003) that the total loss of output due to depression and anxiety was in the region of £12 billion a year (1 per cent of total national income). Of this, the cost to the taxpayer was around £7 billion a year, including incapacity benefits and lost tax receipts. The report argues that some of these costs could be offset by more investment in cognitive therapies which are estimated to have a 50% success rate. It compares the cost of one course of cognitive behaviour therapy (CBT) at £750 with the cost of one month on incapacity benefits - £750 including the fall in tax receipts. It argues that 'from the Treasury's narrow financial point of view, this is a good investment'. The report also points to the savings on NHS services if fewer people require hospital treatment.

- 3.69 There may not be consensus on the strategy of large-scale investment in CBT, and the report does not contain an assessment of the costs of providing the resources for more therapists. But it does put forward an estimate of the overall cost to the Treasury of the high proportion of people with mental health support needs who lose their jobs, or cannot find employment.
- 3.70 A recent report by the Social Exclusion Unit (2006) has provided an estimate of the cost to the economy from the relatively lower employment rate of older workers, including older disabled people. The study put the cost to the economy at £19-£31 billion a year in lost output and taxes and increased payments. It also pointed to the cost to employers who are potentially losing out on skilled workers. The report argues that reduced spending on intensive services, including health services, is among the benefits of increasing participation in society for older people.
- 3.71 Many of the early programmes aimed at delivering independent living objectives originated in USA and Australia and, therefore, some of the large-scale evaluations are from these countries. For example, a comprehensive evaluation of Independent Living Centres by the US Office of Special Education and Rehabilita-

tive Services (2003) highlighted the wide variety of beneficial services and advocacy support being provided and the high level of satisfaction reported by consumers. These Centres enabled consumers to access community facilities and services in a wide variety of areas, including personal assistance, transportation, housing, employment. In terms of macro-level savings, the report also noted that the Centres for Independent Living had enabled 1,380 consumers to leave nursing homes or other institutions to live in the community.

- 3.72 An OECD study (Lundsgaard 2005) comparing long-term care programmes that offer users choice and consumer directed employment of personal assistants, found that the implications for employment and fiscal sustainability of programmes are complex. Giving older people a budget, or cash payments to pay informal care, can help tap into a wider resource where there are shortages of workers. However, a proper functioning market for formal care services is essential to allow relatives of older persons to maintain their attachment to the normal labour market.
- 3.73 Finally, in our consultations with lead researchers in PSSRU and SPRU, it was suggested that net benefit calculations at macro level ought to take into account the benefits to disabled persons and also the additional benefits to informal carers.

## Methodological issues in measuring costs and benefits

### Difficulties in measuring costs

- 3.74 As early as 1970 (Berkowitz and Johnson, 1970), economists had attempted to capture the costs associated with disability. Theoretically speaking, these costs must include both loss in tax receipts, extra transfers towards disability benefits for the exchequer, lower incomes for disabled people than they would otherwise have, out of pocket expenses or direct additional costs of disability as well as the social and psychological costs. However, in reality it is difficult to estimate all these costs.
- 3.75 In surveys, individuals tend to under-report costs, often due to simply reporting on their actual expenditure rather than their needs. In addition, sometimes costs are internalised or opportunity costs are not taken account of. On the other hand, over-reporting can also take place due to the difficulty in estimating the differ-

ences between actual and potential expenditure in the absence of disability.

3.76 Our review of the literature indicated that there are several approaches in use for measuring the extra costs of disability. In an evaluation of the various methods of measuring and estimating extra costs, Tibble (2005) in reviewing research on the costs of disability for the DWP, found that there was no standard definition of costs used by all the studies. Instead, he identified the following approaches with different strengths and limitations:

- The subjective approach asks individuals to estimate what their additional expenditure is due to their disability, or what it would be if they became disabled, and on what items they spend, or would spend, the additional money. Although the key strength of this approach is that disabled people themselves provide estimates, it is often difficult for respondents to report costs accurately and they are likely to underestimate the expenditure associated with their impairment.
- The comparative approach compares spending patterns of disabled people with those of 'similar' non disabled people. The data is more accurate as the actual expenditure is measured rather than using estimates reported by individuals. However, this approach is hindered by not taking into account the impact of income constraints on individuals, which is different for disabled and non-disabled individuals. The approach cannot measure what the potential costs of disability are – i.e. how much respondents would spend if there was no income constraint.
- Studies using the standard of living approach are based on the assumption that disabled people experience a poorer standard of living than non-disabled people with the same income, due to the diversion of money resources to goods and services required by a disabled person.
- The budget standards approach, developed by the Centre for Research in Social Policy (CRSP), is similar to the subjective approach in that disabled people are asked to directly state their needs. Instead of individuals responding in terms of the expenditure they require, focus groups develop an exhaustive list of items that they consider are required for a reasonable standard of living. This approach measures disability related needs, but does not attempt to measure any extra costs.

## Difficulties in measuring benefits

- 3.77 Methodologically, it is even more difficult to value some of the benefits of interventions targeted at disabled people due to the tricky nature of assessing improved quality of life or health status. Moreover, disability issues have traditionally been viewed by successive government as welfare. As such, state assistance to disabled people is seen as a transfer payment, or redistributive costs, with no intended additional benefits. As Frisch (2000) argues, by ignoring the resulting benefits, disability initiatives are not often viewed from an investment perspective.
- 3.78 Zarb (2003) argued for a systematic review of the economic costs and benefits of Independent Living in order to change the focus of the debate and view independent living options as investments that have the potential to bring about both private and social net benefits. He pointed out two key benefits that would require assessment:
- How well particular options satisfy people's needs (measured by reliability, degree of choice, control and independence).
  - The wider benefits that follow from efficiency gains in delivering people's needs (enabling people to take up employment or participate in social or cultural activities etc).
- 3.79 Besides immediate impacts, there are likely to be dynamic, long-term benefits to the exchequer and to society in the form of reduced reliance on health and social care services and reduction in overall dependency on informal support.
- 3.80 The literature on the economic analysis of disability interventions discusses and acknowledges two possible methodologies for measuring benefits (for example in Frisch, 2000 and DeLong 1985) – the 'opportunity cost' concept and the 'willingness to pay' or contingent valuation concept. The former measures potential earnings that would otherwise be lost by disabled people as a result of unemployment or underemployment without the intervention in question taking place. This methodology is more

developed and least complex.

- 3.81 The 'willingness to pay' approach is much less developed. However, it is quoted as being useful for measuring quality of life improvements, which is particularly pertinent for disabled people. This approach generally asks a person to attach a value or price they would be willing to pay in order to receive or avail of goods that normally do not have a market price such as clean air. In the case of disabled people, it can ask a disabled person what they would be willing to pay to avert the risk of having or getting a disability or improving their health outcomes. However, this method is not without limitations. It is often difficult or impossible for individuals to objectively observe or assess the adverse effects associated with disability.
- 3.82 There have been some recent developments in measuring health and social care outputs (Netten et al, 2006 and Burge et al, 2006) by using 'willingness to accept' methods and by asking individuals to put monetary values on levels of need within specified domains, such as social participation, employment, safety, control over daily life. Burge et al (2006) used a survey to collect data on people's stated preferences and developed a model to quantify the value that respondents placed on the domains. This was then used to obtain a monetary valuation of people's willingness to accept financial compensation for any changes within the domains.
- 3.83 However, these methods are relatively new and, certainly, our review did not suggest that there is widespread use of contingent benefit valuation methods in general, particularly the more sophisticated.

## Concluding observations

### Gaps in the evidence

- 3.84 Our interrogation of the literature revealed some clear gaps in the evidence on costs and benefits of independent living at the individual, service delivery and macro-economic level. These are summarised below:
- While many studies are able to capture some of the immediate

benefits of independent living options, very few have managed to deploy robust methods such as willingness to pay or opportunity costs to value benefits quantitatively.

- Although there is no dearth of general data on the costs of disability, some of which indicate that specific elements such as personal assistance and informal care could be significant contributors to overall costs, there is little evidence to suggest what, if any, extra costs, individuals incur under independent living options.
- While some of the overall extra costs for a disabled person are driven by the severity of disability and extent of expressed need, the literature does not provide data or an insight into the impact on individual costs, disaggregated on the basis of specific impairment or age groups.
- There is no systematic comparison of costs and benefits of independent living support options compared with other traditional support in the UK as yet, possibly due to the immaturity of programme implementation and delivery. For example, there is a lack of data on some of the macro level economic benefits of increased participation in employment and education.
- There is very little discussion of macro level benefits to the exchequer and to the society (net social benefits) as a result of independent living support, possibly related to the corresponding lack of evidence at micro (individual and service delivery level) level on benefits.
- It will be important to identify, at an aggregate level, improvements in health outcomes and mental and physical well being as a result of independent living options.



# 4 Case studies

## Methodology

- 4.1 This chapter presents the findings from the qualitative primary research into five different independent living support mechanisms. Five case study scenarios, (as listed below) were selected by the ODI Steering Group. It must be stressed at this point that the case studies are illustrative rather than representative. Examples have been chosen to demonstrate the costs and benefits of using resources to promote independent living, in comparison with a situation where resources are employed more conventionally. This report is not claiming that the case studies are typical or representative. Each one presents unique circumstances but serves to illustrate the potential contrasting costs and benefits.
- 4.2 The five scenarios are:
- Out-of-authority residential placements for disabled young people
  - Disabled Parents
  - Advocacy support to help job retention
  - Institutional Provision
  - Older people
- 4.3 For each case study, the Steering Group provided SQW with a list of nominated stakeholders, which included policy advisors,

academics, statutory and voluntary service providers and experts in the specific IL fields. The exact mix of consultees varied across the five case studies. In addition, SQW researchers also spoke to individuals<sup>9</sup> in receipt of IL support and recipients of conventional care provision in order to facilitate a comparative perspective on the relative costs and benefits of both types of delivery. The majority of consultations were conducted in person, with the remainder over the telephone where this was not possible.

- 4.4 In order to extract the relevant information about the costs and benefits of both conventional support and independent living options, we constructed an aide memoire, which was slightly adapted and tailored to correspond with each type of interview. These discussion guides (which can be found in Annex D) formed the basis for the interviews.
- 4.5 Each case study below details the type of provision, takes an in-depth scrutiny of service recipients' experiences, identifies the costs and benefits of IL and draws a comparison with conventional forms of care delivery. By virtue of the fact that interviewees and circumstances varied considerably, the case studies are unique in their presentation and provide different types of cost and benefit information.
- 4.6 Following the review of the individual scenarios, there is a broader discussion of costs and benefits at service delivery and macro-economic level from evidence gathered in case study and strategic interviews.

## Case study 1: Out-of-authority residential placements

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<sup>9</sup> The names of all individuals that we interviewed have been changed to protect their anonymity.

## for disabled young people

### Introduction

This case study focuses on the provision of further education for young people with learning disabilities. The rationale for investigating this issue, as part of the review of Independent Living, is that it is concerned with enabling young people and their families to have a choice about 16 – 18 provision and make their own decisions and, hence, become independent.

The hypothesis that the case study seeks to test is as follows:

‘Under conventional support services disabled young people aged 16 – 18 and their families are sometimes forced into accepting a residential further education placement, which is not in their local authority. This is necessary because neither suitable education provision nor the support services that would meet their needs and deliver independent living are available locally. These out-of-authority placements are more expensive than meeting needs locally.’

The case study looks at the two different scenarios: one in which services are delivered in the ‘conventional’ way (by this we mean that the young person is in an out-of-authority residential placement) and the other where the family is experiencing independent living support services and their son attends the local college. It assesses the costs and benefits involved in delivering education and support in each of the two situations.

To compile this case study, in depth face-to-face interviews were held with the mothers of the two families. Consultations were also undertaken with two policy officials from the Department of Health and a consultant working on the Individual Budget pilots.

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## Individual scenarios

### Conventional support – Andrew's story

Andrew is 16 and has severe learning disabilities and slight physical impairment. He relies on his family for personal assistance and attends a special school, which also provides holiday and after school activities.

In the county in which Andrew lives, there is no post 16 provision at any of the local education authority's (LEA) special schools. As such at Andrew's 14+ review he and his family were told that he would need to go to a local mainstream further education college. However, his family were not confident that the college environment was suitable or safe for Andrew. They felt there was nowhere in the county that could meet Andrew's complex support needs.

The lack of choice presented forced Andrew's parents down a route that they did not want to take. They began looking into a residential out-of-authority placement for him to continue his education. They eventually found an appropriate residential school 40 minutes away from the family home in the neighbouring county. However, the LEA refused to pay for a residential placement and told Andrew's family that he must attend the local further education college.

Following the LEA's resolution, the local college, to which Andrew was due to be sent, carried out its own assessment. It concluded that attendance at the college would not actually be of benefit to him. This conclusion, combined with a change of personnel at the LEA, prompted the LEA to change its insistence that Andrew should attend college. Instead, it was agreed by the officers that he should stay on at his existing school and that, due to his complex needs, a bespoke course be designed for him.

However, Andrew's parents knew that this was still not the right option as the school had no post-16 expertise so Andrew would be without a natural peer group. In addition, when Andrew reached 16, the after school provision and holiday schemes would cease, which would incur considerable difficulties and costs for his family. The headteacher at the school also advised that continuing his education there would not be an appropriate option for Andrew.

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Andrew's family felt they had no other option other than to employ

an Independent Educational Psychologist and lawyer to continue the fight for adequate further education. Eventually, shortly before the case was due to be brought to a Special Education Needs Tribunal, the LEA called an emergency meeting and backed down. It finally agreed to pay for Andrew to attend the residential school in the neighbouring authority.

Andrew's family has spent two years fighting to get suitable further education provision for Andrew. However, they feel that the present offer is still only the best of a limited range of unsuitable options. His parents say that 'the greatest difficulties have not been coping with his disabilities but the continual fighting for the support he needs.' Andrew's parents feel that they have had no choice regarding his further education and have also been made to fight every step of the way. At age 16 they regard non-disabled young people having a range of options open to them and believe that a similar menu of choices should also be available to non-disabled teenagers so that they can enjoy the same quality of life. Instead, parents of disabled young people are forced to accept what is offered, however inappropriate. In addition, they are sometimes faced with the gruelling experience of a legal challenge.

The best solution for Andrew, his mother believes, would be local further educational provision with a course and support designed around his specific needs. This would enable him to lead a normal life close to his family. She believes that local authorities need to develop some creative thinking about young people with learning disabilities. Facilities need to be flexible to assist those like Andrew with the transition from living at home to living within the community, with essential life skills as the main part of the curriculum. This could avoid young people being sent miles away from their families and would keep money within the county enabling families to retain their caring role for longer.

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Costs

Andrew's out-of-authority residential placement is going to cost the LEA £170,000 per year for three years (£510,000 in total). This will cover the costs for education and therapies.

Andrew's parents have chosen to take and collect him from the school, but ordinarily this cost would have to be met by the LEA. The costs of this have not been quantified, but a driver and escort would be required for each trip.

The financial costs that Andrew's family has incurred in their battle for appropriate placement, due to their lack of choice or control, have totalled £5,000, of which £1,300 was for the Independent Educational Psychologist's fees and the rest was spent on legal costs. A further £2,000 would have been spent if the case had reached Tribunal.

Level	Summary of costs	Total per annum
<b>Service Level</b>	Out-of-authority residential placement: <b>£170,000 per annum</b> (LEA)	<b>£170,000</b>
	(£510,000 over three years)	
	Potential additional cost of LEA providing transportation if Andrew's parents had not volunteered to transport him.	
<b>Exchequer</b>	Disability Living Allowance: <b>£3,330 per annum</b>	<b>£5,670</b>
	Mobility allowance: <b>£45 per week / £2,340 per annum</b> (approx)	
<b>Individual</b>	Independent Educational Psychologist and legal fees: <b>£5,000</b> (one off costs)	
<b>Combined costs</b>		<b>£175,670</b>
		Continued

There are also some unquantifiable and qualitative costs, which need to be considered. During the fight for appropriate schooling

for Andrew, his mother has lost out on potential employment opportunities.

Most significant, however, have been the emotional costs for Andrew and the whole family. The fact that he has to move away from his family on a full time basis is difficult for him to comprehend and he will have to contend with confusion and uncertainty over the coming months during his relocation to Buckinghamshire. It will be also an emotional wrench for his parents. The assessment procedure and battle to secure further education provision from the range of limited options is also emotionally draining and has impacted on the health of the family.

Finally, the pressure has had a huge impact on Andrew's siblings – they have been at the back of the parental queue whilst the search for suitable further educational provision for Andrew has been going on.

#### Independent Living support – Chris's story

Chris is 18 and acquired severe developmental delay following illness as a baby. Chris's family are part of an In Control pilot area and receive an Individual Budget to meet his support needs.

Under the previous conventional service provision, Chris's family felt they had to ask permission just to live an ordinary life. The system created a culture of dependency and, as individuals, they did not have any control and were offered very limited choice. Chris's family referred to it as 'conveyor belt care' and felt that their home and personal life were being invaded by a variety of different people on a daily basis.

Chris had previously been presented with no option for his further education provision other than attending a residential school an hour's drive away from his home. He was not happy there and his connection with his community was getting weaker by the day. His parents also argued that he did not need specialist out-of-authority support – he just needed people to listen and respond to his unique demands and a person-centred approach with support and education designed for him by him.

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When Chris's parents heard about the 'In Control' system of support, they jumped at the chance of being involved and applied shortly

before Chris's sixteenth birthday. A social worker assessed Chris in order to give him an allocation of money from Social Services. Chris's parents also applied to the Independent Living Fund. Having direct control over these funds has enabled Chris's parents to employ four personal assistants, who work on a rotational basis, which allows him to access ordinary social and leisure activities, such as the gym, amusement parks and museums.

Chris's parents approached the principal from the local mainstream further education college which has an inclusion policy. It was agreed that Chris could attend the college, with his own personal assistants to support him. A course was designed especially, four days per week, funded by the Learning and Skills Council. The local education authority is responsible for covering transport costs to and from the school and also currently pays for Chris to undertake voluntary work on his fifth day when not at college.

Chris's mother says that independent living has enabled Chris to become recognised as an equal citizen, someone with rights and who is prepared to take on some responsibilities. She says he has the freedom to live an ordinary life instead of being just part of the service system.

#### Costs

The tables below provide a summary of the costs incurred under each of the different types of support that Chris's family has experienced. Provision of 16+ education for Chris at the college costs in total £36,267 per annum compared to the previous out-of-authority education fees of £60,000. This is saving of £23,733.

The total costs per annum, for both support and education, are very similar under conventional support and independent living arrangements. However, the key difference to Chris and his family is the flexibility afforded by the In Control and ILF payments.

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Level	Summary of costs under the conventional	Total per annum
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support system		
Service Level (education)	Out-of-authority residential placement: <b>£60,000 per annum</b> (LEA)	<b>£60,000</b>
Service Level (social services)	Social services expenditure	<b>£15,340<sup>10</sup></b>
Exchequer	Disability Living Allowance: <b>£3,057 per annum</b>	<b>£4,578</b>
	Mobility allowance: <b>£1,521 per annum</b>	
<b>Combined costs</b>		<b>£79,918</b>
In addition to the above costs, on an individual level, Chris's family had to pay for respite care on a weekly basis when they required it.		
Level	Summary of costs under the conventional support system	Total per annum
Service Level (education)	College attendance (4 days per week): <b>£15,723 per annum</b> (LSC)	<b>£15,723</b>
	Transport to college: <b>£10,957 per annum</b> (LEA)	<b>£20,544 (LEA)</b>
	Voluntary work (1 day per week): <b>£9,587 (LEA)</b>	<b>£36,267 (Total)</b>
		Continued
Level	Summary of costs	Total per

<sup>10</sup> Chris's parents estimated that the costs of social care to social services were approximately the same as the costs of the In Control payment – the crucial difference is that there was no flexibility over the way in which this could be spent.

	under the conventional support system	annum
<b>Service Level (social services)</b>	Social services (in Control) allowance	<b>£15,340</b>
<b>Exchequer</b>	Independent Living Fund: <b>£19,986 per annum</b>	<b>£28,690</b>
	Disability Living Allowance: <b>£3,057 per annum</b>	<b>£4,578</b>
	Mobility allowance: <b>£1,521 per annum</b>	
	Youth and income support <sup>11</sup> : <b>£4,126 per annum</b>	<b>£4,578</b>
<b>Combined costs</b>		<b>£80,297</b>

<sup>11</sup> Chris was eligible to receive these payment when he became 16.

## Case study 2: Disabled parents

### Introduction

This case study focuses on parents with learning disabilities, and the support which can be provided to enable them to look after their own children. Whilst there is a growing body of literature in the field of support for parents with learning disabilities, it is still an area which is continuing to evolve as professionals across disciplines recognise the need to gain complementary skills.

There are no precise figures, but it is apparent that increasing numbers of people with learning disabilities are choosing to become parents<sup>12</sup>. However, for a variety of reasons – including a lack of co-ordination between professionals in different services, stereotyped or dated thinking and a lack of resources – many parents with learning disabilities have, in the past, not been offered the type of support (or sufficient timely support) to enable them to adequately carry out a parenting role. Frequently this means that children are taken into care. A national survey found that 48% of parents with learning difficulties interviewed were not looking after their own children<sup>13</sup>.

“People with learning disabilities can be good parents and provide their children with a good start in life, but may require considerable help to do so. This requires children and adult social teams to work closely together to develop a common approach. Social services departments have a duty to safeguard the welfare of children, and in some circumstances a parent with learning disabilities will not be able to meet their child’s needs. However, we believe this should not be the result of agencies not arranging for appropriate and timely support.”

(Department of Health, Valuing People: A New Strategy for Learning Disability in the 21<sup>st</sup> Century, 2001, para 7.40).

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<sup>12</sup> In one recent study, around one in 15 of the adults interviewed had children (Emerson, E., Malam, S., Davies, I. and Spencer, K., Adults with Learning Difficulties in England 2003/04, 2005).

<sup>13</sup> *ibid.*

The case study will seek to test the following hypothesis:

'That support delivered at lower levels than current eligibility criteria for either adults' or children's services, and which addresses all aspects of a family's needs in a co-ordinated and holistic way, enables parents to look after their children and safeguards children's welfare. This prevents higher costs incurred through meeting support needs (including accommodation or adoption of children) when a family is in crisis as a result of lower level support not being provided or being provided in an uncoordinated and fragmented way.'

The case study involved a brief literature review followed by discussions with a series of stakeholders in Stockport:

- a visit to a family (both parents have learning disabilities) who have experienced having their children taken into care several times, as well as having early support which has enabled them to look after their daughter;
- a Social Worker in the Community Learning Disability Team (CLDT), Stockport Social Services;
- an advocate;
- the Head of Children's Services, Stockport;
- the solicitor for the family;
- the local authority foster care team.

This case study is built on two alternative scenarios when a woman with learning disabilities becomes pregnant:

- 1 The removal of a baby into care, followed by adoption – conventional support scenario.
- 2 Support provided to enable the parents to keep the child – Independent Living scenario.

In both instances, the case is assessed by the Children's Team, significant concerns are raised about parenting capacity and it is decided that the child may need to be adopted.

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### Individual scenarios

#### The removal of a baby into care – conventional support scenario

In a 'conventional scenario' a foster family will be quickly identified for short-term care of the child; this may be another member of the child's family, a friend or relative or a local authority council foster-carer. It is very unlikely that a baby will be placed a local authority area or in agency foster care; where possible, the parents would be allowed to visit the child five days per week to maintain the parental attachment. The cost depends on the agreement made with the foster carer and it is not common for the child to be fostered long-term, particularly for babies.

In the case study we have assumed that the child is fostered, using the most expensive option of a local authority foster carer, for a year whilst the decision is made on the next step. The child may subsequently be adopted, which will usually involve legal proceedings. These can vary hugely in cost, depending on the complexity of the case, but the scenario presented here is of a relatively straightforward adoption with no legal 'wrangling'. (If the case were to go to the High Court, then barristers etc. can push the costs up towards £500,000). Where children remain in local authority care (which is more common in the case of a child rather than a baby), average costs for residential care are approximately £2,100 per week; for foster care costs are in the region of £438 per week (Curtis, L. and Netten, A. 2004. Unit Costs of Health and Social Care, Canterbury: University of Kent, PSSRU).

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Independent Living support – fostering, followed by the parents keeping the children

The 'independent living' scenario comprises advocacy support pre-birth and an Adult Social worker and advocacy support during the period of fostering. It also includes a residential assessment, and at-home support of diminishing intensity over a period of several years. It should be noted that this scenario concerns a situation where the parent requires a high level of support until the child goes to nursery (at 4 years old).

It should be noted that for a family to be 'eligible' for the above support arrangements, certain circumstances must exist (i.e. it cannot happen in every case). It must be demonstrated that the following is in place (either from the parents directly, or 'plugged' with service provision):

- capacity for emotional support;
- capacity for physical support (i.e. childcare skills);
- capacity for financial support.

A full costing table with assumptions and in depth details of the quantifiable costs involved in delivery of the two different scenarios is included in Annex E. Below is summary table of these costs, which shows that Independent Living emerges as slightly more cost effective than the conventional system of support.

#### Summary of costs

Traditional Support System (fostering, followed by adoption)	£113,582
Independent Living (fostering, followed by parents keeping child)	£106,614

### Case study 3: Advocacy support to help job retention

#### Introduction

The focus of this case study is on advocacy support, delivered by a user-led organisation to help people remain in employment. The hypothesis is that the provision of support (information, advocacy support and access to relevant services) to disabled people at risk of losing their jobs increases job retention. This prevents costs to the individual, service providers and to the Exchequer that are incurred through loss of employment. The rationale for focusing on an advocacy approach is that is concerned with enabling people to make their own decisions and represent their own interests, and through this become independent.

Breakthrough UK was selected by the ODI for this case study as it runs an advocacy project - the Independent Employment and Advocacy and Information Project - which supports disabled people to access any services and information necessary to find or retain employment or training. A majority of disabled people control and manage the company. The aim is to deliver services that promote and support independent living for disabled people.

The Advocacy project aims to help disabled people with their employment issues by addressing the obstacles they are encountering. The project adheres to a social model of disability and seeks to assist clients to address the multiple barriers they may face in participating in the workforce, including debt, housing, benefits and transport, as well as any barriers within the workplace.

The approach of the project differs from the traditional sources of support that disabled people might attempt to access in order to find or retain work. Instead of providing specialist support in areas such as housing, employment or transport in isolation, the advocates work with their clients holistically – i.e. to support them overcome all the barriers that they are encountering. A second and important difference is that the focus is not just on providing advice and information, but on supporting clients so that they can make their own decisions and take control of their lives.

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This case study investigates the impact and the outcomes of the advocacy support approach in assisting people to retain their employment. It is not possible to construct a scenario which directly

compares the situation of people who do not have access to this kind of support with those who do. However, what is possible, and what we have sought to do, is provide some indication of the costs and benefits of the support provided, and the costs incurred when people lose their jobs.

The case study methodology consisted of in-depth interviews with the following individuals and workers at Breakthrough:

- The project manager.
- The information worker.
- An advocate.
- A client.

Breakthrough also provided a detailed individual case study of another client, whom it was not possible for us to interview. In addition, the policy officer at Mind<sup>14</sup> provided a strategic overview of the employment barriers faced by people with mental health problems and the principles of advocacy support. Employment rates for disabled people vary according to the type of broad impairment category, and people with mental health problems have the lowest employment rate at 20 per cent. Mind has recently published recommendations concerning advocacy services based on the experiences and views of people with mental health support needs<sup>15</sup>.

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### Individual scenarios

#### Independent Living support

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<sup>14</sup> Mind is a leading mental health charity that campaigns on behalf of people with mental health support needs.

<sup>15</sup> Mind (2006), *With us in mind*, Service user recommendations for advocacy standards in England.

The Advocacy Project has supported 120 disabled people between November 2003 and May 2006 with ongoing independent employment advocacy. It has also worked with 500 organisations and companies to provide good practice information on employment.

The sources of referral include self-referral, word of mouth, other agencies, government departments, and specialist disability organisations. Many people come with job related problems, such as not getting the reasonable adjustments that they need. However, many others are having difficulty holding down a job because of barriers they face outside the workplace, such as housing problems or financial difficulties. The two advocates working in the project are not specialists in a particular area; rather they look at the range of problems and barriers each individual client is facing and address the specific set of needs and circumstances.

Although details are collected on each individual client's situation and an action plan drawn up, the project has not to date collected information on all aspects of the person's financial circumstances. The project is entering a new phase of funding and will commence the collection of specific data which will provide for a systematic evaluation of the outcomes of the project. In particular, weekly statistics will be compiled showing the numbers who have found or retained employment. There will be more information relating to any changes in the level of benefits, and on other elements of financial support such as debt management. It will also be possible to calculate the cost of support for each client via the information collated on the number of hours worked with a specific client.

Without access to this level of data at present, for this case study, the project provided as much detail as possible to show the benefits and outcomes for one of their clients (Lee) of retaining his job. SQW also interviewed another client (Anna) who provided some financial information. In her case, as in the case for many of the clients that the project supports, the perceived benefits are as much related to improved quality of life, ability to take control over decisions, and

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improved mental and physical well-being, as to any financial benefits. However, every case where an individual disabled person is able to retain their job, involves savings to the Government, as discussed

below.

Two individual client cases are outlined. Client 1 is based on Breakthrough's anonymised case notes. Client 2 is based on a detailed interview with the client.

### Lee's story

'Lee', who has a learning disability, was referred to the advocacy project after his father died, and when he was facing multiple barriers. When he first came to the project he was in a very distressed state. He had got into a lot of debt and fallen behind with his rent so that he faced eviction. Lee was also frequently absent from work, and, when he did attend, he was often under the influence of alcohol. Eventually he was placed on a final written warning. He was at risk of losing his home, his job, and possibly the shared custody of his son. His health was also deteriorating and he did not understand the letters that he received from his landlord or officials. Under all these pressures he began to drink heavily and expressed suicidal feelings. Lee had no support network to deal with the range of problems that he faced.

When Lee was referred to Breakthrough, the advocate focused on building up a rapport with him and discussing the different ways in which he could address the problems he was encountering. One big barrier was that the information being sent to him in letter form was inaccessible; he did not understand the significance of the correspondence or what he was required to do. The advocate was able to explain everything in plain English and she also accompanied him to a court hearing and meetings with a solicitor.

With her support, Lee started attending bereavement counselling, completed and maintained an alcohol detoxification programme, attended sessions with a debt counsellor and put in place payment plans to deal with bills and creditors. The advocate also helped him improve his income by applying for unclaimed tax credits, and housing benefit. It emerged that Lee's employer was completely

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unaware of the problems that he was dealing with outside work, or the extent of his emotional stress. With Lee's permission, the advocate explained all this to the employer, which helped him to

keep his job.

Two years after contacting Breakthrough, Lee continues to work full time. His employer commented that without the support provided by the advocacy project, Lee would definitely have lost his job.

#### Costs

The following table summarises the costs involved in providing advocacy support for Lee.

Cost	Estimated amount	Notes
460 hours of a support worker's time over a 10.5 month period	<b>£3, 841 gross salary</b> (excluding employer's contributions)	Additional support was provided by the Project

co-ordinator and line manager, which has not been costed

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#### Benefits

The table below shows the quantified benefits that Lee experienced as result of the advocacy project. He was able to retain his £8,840

annual income, access over £4,300 in tax credits and also received £225.50 in backdated housing benefit.

Benefit to individual	Estimated amount	Notes
Retaining job	Weekly wage: <b>£170 net per week</b> (plus any overtime)	£8,840 net per annum
Tax credits (for which he had previously not applied)	<b>£82.81</b> per week	£4,306.12 per annum
Backdated Housing Benefit (to which he did not realise he was entitled)	£225.50	One off
Council Tax arrears written off	No figure available from case notes	One off
<p>The advocacy support also helped to develop a manageable payment scheme to deal with his £9,000 of debt; this helped to avoid fines for bills such as his television license (potentially a £1,000 fine).</p>		
<p>It is worth noting that Lee also experienced some additional non-quantifiable and important qualitative benefits. He was able to find somewhere better to live, which was closer to work and his mental health improved.</p> <p>As well as the individual benefits to Lee of retaining his job, there are also benefits at Exchequer level. The table below highlights that £9,593 per annum is saved by Lee remaining in employment due to the tax revenues that he can contribute and the benefits he does not need.</p>		
Continued		
Exchequer saving	Estimated amount	Notes
Incapacity Benefit	<b>£4,500 per annum</b>	

Housing Benefit	<b>£2,600 per annum</b>	
(based on a low rent of £50 per week with a social landlord)		
Tax revenue that would have otherwise been lost in case of non employment	<b>£2,493</b>	Based on 22% income tax rate, assuming gross annual salary of £11,333
		Note this does not include NI contributions
<p><b>Anna's story</b></p> <p>'Anna' is a woman with a physical impairment which affects her mobility. She came to the UK approximately 10 years ago and is married with two young children. When she contacted the advocacy project, she was having difficulties at work because her needs as a disabled person were not being met. She was unable able to access the building easily and flexible working was not available. She then had a fall at work and her employer expected her to use her annual leave for physiotherapy. She was experiencing physical stress and on the verge of resigning.</p> <p>Through the support of the advocacy project, Anna was able to retain her job and then, when the difficulties persisted the following year, she resigned and the advocate supported her in finding alternative employment. In her new job, she has also encountered barriers arising from the physical inaccessibility of the workplace and her employer's failure to make adjustments to enable her to continue working there. With the ongoing support of the advocate, she is staying in her job while actively seeking another one.</p> <p style="text-align: right;">Continued</p> <p>Anna feels that the support she has received from the advocate was vital in enabling her to stay in employment. She described herself as confident in terms of her qualifications (she holds a professional qualification), but her employer had made her feel</p>		

~~that she deserved what happened to her because of her disability.~~  
In contrast, the advocate kept reminding her that the problem did not lie with her, but with the barriers she encountered in her employment. Anna mentioned that the Disability Employment Advisor at Jobcentre Plus could provide help to get as far as a job interview, but could not deal with the type of problems she faced in retaining her job.

Anna was clear that the support had made a major difference and provided a small amount of financial information. Without the support she received, she would have resigned from the job due to stress and would then have been unable to keep up with mortgage payments. As she and her family had experienced racial abuse on the council estate where they lived previously, it was important to her that she was able to keep her home in a neighbourhood where the family was happy: "The children are able to play outside. We feel part of society and more integrated."

Anna had been on Incapacity Benefit before she got her first job. For her, coming off benefit was important because it had improved the quality of her life. She said that she had seen being on benefit 'as a life sentence and a judgement that I was incapable.' To her, independent living means 'being able to earn my own living and to have choices – how to spend money, where to live, wider horizons'.

#### Costs

The advocacy project was not able to provide any financial information on the costs of providing advocacy services to Anna.

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#### Benefits

As the table below shows, in the case of Anna's family, the benefits of retaining her job are £28,587.50 per annum.

Benefit to individual	Estimated amount	Notes
Retaining job	Salary: <b>£11,587.50 per annum</b>	
	(Anna earns £23,175 pro rata gross per annum – she works 2.5 days per week)	
Retention of spouse Income	Salary: <b>£17,000 per annum</b>	While Anna was not employed and was claiming Incapacity Benefit,
her husband was on JSA. He got a job when she found employment.		
<p>The qualitative benefits of the advocacy to individuals must not be overlooked. For Anna, retention of employment has enabled her to maintain her mortgage payments and, as such, keep her family home.</p>		
<p>The advocacy project is concerned with enabling people to become more confident and represent themselves. The project manager at Breakthrough reported that 'moral support is the greatest issue. We know this because we ask what people need and this is the response most frequently given.' It is also completely person-centred, as summed up by one of the information workers: 'We look at the person as a whole. We ask people about the barriers they face, rather than asking about their impairments. It is about how they experience the barriers. It is a person-centred approach. Many of the people who work at Breakthrough are disabled themselves, so we know collectively that the barriers are real and multiple. It is not just a case of finding a job, but of building confidence and self-assertiveness'.</p>		
Continued		
<p>The table below shows that, at the level of Exchequer, £19,498 is saved by Anna and her husband being in employment. In addition, these figures are based on 2002 rates so are likely to</p>		

have increased.

Exchequer saving	Estimated amount	Notes
Incapacity Benefit (for herself) and Job Seekers Allowance (JSA) (for her husband)	Joint payment: <b>£300 per fortnight/£7,800 per annum</b> (approx)	Based on Anna's 2002 income
Housing Benefit	<b>£55 per week/£2,860 per annum</b>	Based on 2002 benefit income
Council Tax Benefit	<b>£70 per month/£840 per annum</b>	Based on 2002 benefit income
Tax revenue that would have otherwise been lost in case of non employment	<b>£5,098 for Anna, per annum</b> <b>£3,740 for spouse, per annum</b>	Both assuming 22% income tax rate and not including NI contributions

Cast study 4: Disabled people with high levels of support needs in institutional provision

Introduction

This case study focuses on institutional care provision and the option of independent living as an alternative. It examines the perceived and experienced costs and benefits of both forms of provision and discusses some of the issues raised when considering or experiencing the move from institutional care to independent living and the barriers faced.

It explores the hypothesis that people with high levels of support needs, associated with physical/sensory impairment and/or learning disability and/or mental health, are forced into institutional forms of provision, which is both more expensive, and delivers fewer benefits than providing support enabling them to live in the community.

The case study involved a review of publications and research articles recommended by the ODI for the case study, as well as selected documents arising from the main literature search. This was followed by in-depth interviews with key policy experts and two individuals who have direct experience of institutional provision, one of whom has been able to secure independent living arrangements and one who has not.

## Individual scenarios

### Conventional support – Michael's story

Michael is 28 years old and has a progressive neurological condition, which required him to move into residential care at the age of 23 in 2001. He requires 24-hour care to get up, go to bed, cook, go to the toilet, and other personal assistance including accompaniment when leaving the home. Michael shares a partially self-contained flat with one other resident. The flat is linked to the residential care home permitting 24-hour care, but also offering some degree of privacy. Whilst Michael acknowledges that this type of provision is better than many residential care homes, it still does not offer him the independence he desires.

Continued

Michael is in receipt of Income Support and Disability Living Allowance. The home costs are funded partly by Social Services, partly by contributions from his Income Support and partly by the care element of the Disability Living Allowance.

Michael is currently a voluntary teacher at the local primary school and undertakes web design for various charities and voluntary groups on a voluntary basis. However, due to rules on personal expenses allowance, Michael would only be able to keep £18.90 of any income he earns. As such, he feels unable to earn an income for himself through paid work, despite having received job offers and having the ability to undertake consultancy style employment.

Michael does not want to live in residential care and would like to be able to work, which would enable him to contribute to the exchequer and his future pension as well as play an active role in society.

#### Costs

The following table provides the costs of Michael's conventional support package.

Cost	Amount	Notes
Residential care home	<b>£950 per week/ £49,400 per annum</b>	Funded partly by social services, personal contributions (income support) and the care element of his disability living allowance.

Michael also personally bears the cost of some of his equipment needs and pays £15 per month to subscribe to the homes' transport services, plus an additional 40 pence per mile for any journeys undertaken using this service. Despite the subscription charge, use of this service is highly dependent upon the availability of staff and the cost of this support is high (£20 for a trip to the nearest city centre in addition to the monthly subscription). In addition, Michael

Continued

regularly holidays at an activities centre for disabled people in Northumberland, which he funds himself at the cost of £700 week (this is less than the cost of one week in the residential care home), including board, activities and care support. As a consequence of not being able to take up paid employment, Michael is losing out on potential earnings, which is a personal cost to him, as well as a

loss in potential tax revenues to the Exchequer.

Significantly, Michael stresses that the emotional and mental costs of living in residential care cannot be underestimated. His current living arrangements prevent him from participating society as he would wish. Michael believes that regardless of the quality of the care home, there are huge impacts on an individual's mental health when they do not have direction over their care and their environment. Michael finds this lack of control very frustrating and his mental health has declined as a result, particularly a year ago when he became very depressed.

Michael highlights the limitations of institutional care. If he wants a holiday, the carer provided by the home can not accompany him, nor is he able to use the funds that would be paid to the care home for the week. The reality is that Michael either has to bear the additional cost of funding carers to accompany him or rely upon friends and family members. If Michael was using Direct Payments, he would be able to employ carers to accompany him on holiday.

Michael feels that living in residential care has a huge impact on his social relationships and social participation in a number of different ways. In order to go out, Michael needs to be accompanied. However, due to the nature of his support needs, this is only possible when there are sufficient carers available at the home, which often does not coincide with the times he would like to go out. As a resident of institutional provision, Michael has very limited influence on where he lives; his friends live approximately 40 minutes away in the nearest city and the limited transport options available to him severely restrict his access to them.

Michael also highlights the social stigma associated with living in residential care, with society making negative assumptions about his abilities. A common assumption is that people living in residential care do not have relationships. For example, the care home provides only single beds in single rooms; acceptance of lesbian, gay and bisexual relationships is even less likely.

Continued

### Benefits

Michael acknowledges that living in residential care does provide him with the security of 24-hour support and on call staff. The prospect of living independently is daunting, particularly after a number of years in residential care. The care home is responsible for everything that is provided. Independent living would shift this burden of

responsibility to him as an individual, a prospect which should not be considered lightly.

### Independent Living support – Emma’s story

Emma is 45 years old and has cerebral palsy, requiring a 24-hour care package to support her needs. She lives independently in an accessible ground floor flat in North London. Prior to moving here, she had spent the majority of her life in a succession of Barnardo’s homes and residential care homes.

Originally, Emma’s care package and support workers were provided by an organisation which was paid by the local authority directly. This organisation has since closed down and Emma has moved onto the Direct Payments scheme. Emma employs six staff, of whom four came from the previous care provider; the other two were introduced to Emma by her existing care workers. Independent living does not offer the opportunity of wage gains for Emma as she is unable to work. She is in receipt of housing benefit and income support.

She feels that the transition from institutional provision to independent living has been a smooth one.

#### Costs

Cost	Amount	Notes
Care costs	<b>£1,000 per week/ £52,000 per annum</b>	Funded through her Independent Living fund and Direct Payments. Emma makes a weekly contribution of £75.80 per week.
also		

Continued

For Emma, it feels as if Independent Living personally costs her more than living in residential care as she is required to make a contribution of £75.80 per week to her care costs, which she did not have to make when in residential care. However, had she remained in residential care, she would not actually have had £75.80 to contribute in the first place as, like Michael above, she would only have had a maximum £18.90 per week personal expenses allowance.

Emma uses a payroll agent to administer her Direct Payments; she sends timesheets to the agent who pays the worker and then bills Emma. There is a small fee for the service, for which the local authority has made provision within their funding allocation.

Emma acknowledges that Independent Living is not an easy option as it requires the individual to be able to budget, be financially aware and responsible. There are payroll agents who can be used to manage and assist the process, but individual confidence and understanding of the process is also required.

### Benefits

The overwhelming benefits of independent living are emotional and social. Emma is definitely more satisfied with living independently rather than in residential care. Her quality of life has improved significantly since living independently. It is often the simplest things that make the greatest difference; Emma is able to choose when to get up, what to watch on television, what and when to eat and she is able to furnish her home as she chooses and have pets.

As a result of the opportunities that Independent Living affords her, Emma believes that she is more outgoing and confident. Emma feels that she is part of a community; she is now able to attend church, the local gym and other shops and services. She is accepted by her those living around her as part of her neighbourhood.

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### Concluding observations

On an individual level, Emma is slightly worse off living independently due to the weekly contributions she has to make from her Income Support to fund her care package (amounting to approximately £3942 per annum). However, she reports that this cost is far outweighed by the costs to her mental and physical well-being that she would incur by living in residential care. During her time in residential care, Emma was prone to severe depression, frustration

and, at times, inappropriate behaviour because she was not able to express herself or have control, choice and independence in her life. She believes that if she had to return to residential care, she would lose her sense of individuality, choice and freedom.

Michael shares many of Emma's views. He acknowledges that Housing Benefit would probably not cover all of the rent costs he might incur living outside a care home, so he might have to supplement it. Michael also accepts that he would incur time costs in terms of organising his care package but knows that he could employ an agency to support him.

However, although an Independent Living arrangement might cost him more in basic monetary terms initially, he believes in the longer term he would be able to keep more of his earnings so that he could be better off. The greatest perceived benefit, however, would be to his overall quality of life. Michael would be able to 'normalise' his relationships with his family and friends through reducing his reliance upon them, have more control over the quality of the care provided for him, and be able to significantly increase his opportunities for social and labour market participation.

## Case study 5: Older people

### Introduction

This case study focused on Independent Living for older people. It sought to test the hypothesis that: 'Access to low level, preventative support that is locally and community based (and culturally sensitive) can enable older people to retain and enhance their independence, assist them to stay living in their own home, improve reported

wellbeing, promote greater levels of “functioning”, and improve individuals’ health status.’

Central Government policy, supported by research findings in recent years, emphasises the need for local agencies to plan for and provide a wider range of opportunities for older people to live independently. The rationale behind this approach is to reduce the need for acute care (hospital admissions, particularly emergency admissions and unplanned readmissions), intensive social services interventions and admission to residential and nursing care homes through earlier ‘preventative’ interventions which decrease the likelihood of ill-health and disability in later life; improve quality of life for older people who have health problems or chronic or deteriorating conditions; and enhance overall health and wellbeing for all older people. This, it is argued, is a more cost effective way of allocating scarce health and social care resources; as well as broadening the range and types of support typically available to and accessed by older people. A recent report for the Joseph Rowntree Foundation based on an Older People’s Inquiry into ‘That Bit of Help’ provided many examples of low-level support options that older people themselves wanted, which could enable them to remain independent (Raynes et al, 2006).

A key challenge is in reversing decades of ‘traditional’ provision that has resulted both in a narrow range of support being provided (e.g. home care, attendance at day centres, residential care), and a tendency not to include older people in decision-making decisions about the support they receive and, therefore, lifestyle they are able to lead.

A range of academic, Government and third sector studies strongly put forward the argument for decision makers to value both the quality of life of older people and support that optimise opportunities

Continued

for independent living. Crucially this means listening and responding to the views and opinions of older people themselves. There has been a slow reaction to community care reforms of the 1990s, which put in place the legal framework enabling local authorities to provide independent living options<sup>16</sup>. The service deliverers consulted as part of this case study agree that there needs to be a shift away from an unsustainably high level of spending on acute services, which allow

older people's quality of life to degenerate and thus place more pressure on health and care services. In its place there needs to be a system of earlier and lower level (and lower cost) interventions.

The approach adopted for this case study was slightly different to the other four scenarios. Projects designed to deliver preventative services for older people, rather than specific individuals, have been studied, although service recipients of one of the projects were also directly consulted (a small focus group was held with older people who are beneficiaries of a scheme to promote independent living in Portsmouth).

The case study is divided into two parts to examine two different projects which, through their preventative interventions, seek to promote and secure Independent Living:

- The Portsmouth Prevention and Wellbeing Network – a local network, which aims to empower older people to access independent living. Three individuals involved in the network were consulted and information required to undertake cost benefit analysis of this initiative was identified.
- The Dorset Partnerships for Older People Programme pilot initiative – which incorporates an account of the projected savings in acute services.

Continued

### The Portsmouth Prevention and Wellbeing Network (PPWN)

The PPWN is a network of service commissioning authorities, statutory and non statutory service providers and older people. It is resourced and facilitated by Portsmouth City Council and meets twice a month to share experiences and concerns and ensure that the views and aspirations of local older people shape delivery of services. The Network also supports a number of opportunities for

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<sup>16</sup> Local Government Association and the Association of Directors of Social Services (2003), All Our Tomorrows: Inverting the triangle of care.

older people to meet together, pursue common interests and provide peer support (e.g. through local clubs spread across the City). The Network aims to ensure that healthy active ageing, well being, choice, dignity and respect are at the heart of the development and delivery of all services for older people in the City.

Three women over 65, all of whom live alone and benefit from the PPWN, described the different ways in which it has maximised independent living for older people. Claire previously lived in an Outer London Borough. She moved to Portsmouth a few years ago after her husband died, to be nearer her daughter. Shortly after moving to Portsmouth, Claire was admitted to hospital for a hip replacement and following a number of complications spent almost a whole year in hospital and rehabilitation settings.

Whilst in hospital, Claire met Pat, who has lived in the area all her life. Pat introduced Claire to the Wednesday Club (part of the PPWN) and the wider web of support services available to older people through the Network. They met Joan through this club who, has difficulty walking more than a short distance, but has no need for assistance within the home.

All three women use the 'Wednesday club' organised by the network, which provides physically and mentally stimulating activities, as well tailored support on a personal level. PPWN also facilitates community group meetings at local venues close to where people live so that they are accessible.

There is a free transport service that Claire, who has a mobility impairment following her hip replacement, uses to take her to medical appointments, the 'Wednesday club' and the shops once a week. Claire receives visits from a support worker once a week who

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helps with some domestic tasks, but she also employs a cleaner privately, which she says is affordable as the local authority covers the costs of the other services she receives.

Pat described the Homecheck home improvements scheme, available to all households in the city where one resident is over 60. This is funded entirely by the Council. Following a comprehensive assessment of the home, any work required to bring the house up to a certain standard is arranged. The cost of this work is paid back

when the house is sold. As such, it is essentially an interest free loan. This scheme includes a Handy-Man service for minor jobs, small scale maintenance and repairs. This service is free to older people and is not subject to any means test. Those using the service vouch for its positive impact in preventing accidents as a result of improving unsuitable or unsafe housing conditions.

These women, living alone and each with various health needs/mobility constraints now have access to an active network of friends and activities as a result of the PPWN; this social interaction has an impact on their quality of life and wellbeing. All three agree that the PPWN in Portsmouth provides them with a range of opportunities and practical support to live independently. Claire is also clear that such assistance would not have been available in her previous borough, unless she paid for it herself.

#### Costs and benefits

There are considerable quality of life benefits to older people in Portsmouth, including improvements to mental well-being through friendships they form. Those involved in the Network highlight the social and emotional benefits as well as the practical assistance available. In addition, older people are actively engaged in shaping the services that they receive and the way in which they are provided. In particular, the peer support to both access and receive help through different Independent Living schemes helps to build confidence and trust and, therefore uptake.

The services provided as part of PPWN also represent cost and time savings for family, neighbours and friends. Older people in receipt of the services are not only living independently in a physical and financial sense, but they are also less reliant on informal support from their neighbours and family members.

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The qualitative benefits of involvement in PPWN, based on the perceptions of those recipients that were interviewed in the case study, are well documented above. The data we were presented with for this case study, however, did not include details on the costs of providing the service and the way in which this compares to more traditional modes of delivery. In order to test the extent to which this provision offers value for money, an analysis of savings in terms of acute provision (hospital admissions, residential and nursing homes

etc.) offset against the level of resources invested into the PPWN would need to be conducted.

### Partnerships for Older People Programme (POPP) pilots

POPP is a national initiative, announced in 2005 and funded by the DH. The first wave of this programme began in April/May 2006 in 19 pilot localities across the country. Another 11 pilots will be selected in December for phase two, which will commence in 2007. Significant resources have been invested at a national and local level to ensure creative, joined up approaches to preventative services and support at a local level to meet the specific needs of the populations involved. The central aim is to facilitate a shift from traditional allocation patterns, in which resources are tied up in acute, secondary care services for older people, towards a wider range of flexible and preventative services engaging a broader spectrum of partners and stakeholders. The idea is that savings accrued in the acute sector (due to reduced admissions and positive impacts on local populations of older people) will be invested in primary and community based services and support.

Dorset County Council and its NHS and voluntary sector partners are one of the 19 POPP pilots. Its scheme is ambitious and wide-ranging. It is designed to harness the personal and collective resources of people over 50, across the county, in the provision of peer support, brokerage, social networks, local community development projects, and in the commissioning intelligence to inform the future development of services based on "what works" for local older people.

Continued

The total investment over two years in Dorset is £2.4 million. Each year the majority of this money has been allocated for new posts employed by the Council with a focus on community development and regeneration (rather than traditional social care/care management positions). In addition, 114 older people have been employed by a range of non statutory organisations and community groups as wayfinders, local leaders and local evaluators.

Examples of the savings that the project is expected to make are set

out in the table below. Over the first four years after implementation savings are forecast to total £4.87 million. This is double the initial grant of £2.4 million. As such, the case study illustrates the potential for an approach based on promoting earlier intervention which enables older people to access independent living, to provide substantial service level savings.

Median Maximum Savings Area Year 2 Year 4	Minimum Maximum		
	Year 1 Year 3		
	no.	£	no.
£	no.	£	no.
£			

Hospital bed days (£220 per day) 348,480	792	174,240	1,188	261,360	1,584	348,480	1,584
A & E Attendance (£117 per day) 138,996	396	46,332	792	92,664	1,188	138,996	1,188
Nursing Home Care (£16,700 per year) 300,600	6	100,200	12	200,400	18	300,600	18
Res Care Placements (£15,700 per year) 282,600	6	94,200	12	188,400	18	282,600	18
Staff time re Residential/nursing packages (£225 per year) 7,920	12	2,640	24	5,280	36	7,920	36
Staff time Re: reduction in referrals (£53 each) 3,816	24	1,272	48	2,544	72	3,816	72
Home care packages (£36 per week) 185,328	33	61,776	66	123,552	99	185,328	99
Meals delivered by in-house home care (£6.22 per visit) 245,168	758	245,168	758	245,168	758	245,168	758

Total Savings	725,828
1,119,368	1,512,908
<b>1,512,908</b>	

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Source: Dorset Partnerships For Older People Projects 2006 – 2008  
- Proposal Document

## Findings from the case studies: the Bigger Picture

### Conventional support

#### Service Delivery Level – Costs

- 4.7 Much evidence from the case studies and consultations makes reference to the variety of inefficiencies involved in the delivery of conventional types of support. Stakeholders suggested that 20-30% of social services expenditure is wastage. Local authorities are encouraged to enter into block contracts for services which offer initial cost savings, but limit flexibility and incur greater costs in the long term. In addition, local authorities often deliver their care services through employment agencies, which make significant profits on delivery. One consultee highlighted the fact that agency charges for care services are typically £15/16 per hour, though care workers themselves are only paid approximately £6. Whilst some of the additional charge covers administration and management, there are still considerable profits involved.
- 4.8 Several interviewees mentioned the inefficiencies of the way in which disabled people's needs are assessed. They commented that this can often result in disabled people receiving a level of care which is over and above their actual needs and that this can represent a major cost. There is standardisation to reduce unit costs but, because providers are generally risk averse, care is provided at a higher level of support than is actually required. In addition, particularly, in the case of older people, there is a tendency for an individual to agree to an intervention or professional recommendation even if they are not happy either because they are not provided with any other options or they fear that they will not receive any further support if they refuse what is offered. Non-inclusion of individuals in decision-making, therefore, can result

in interventions being provided which are not necessarily what individuals want or need. It often emerges that equipment sent to individuals by the NHS or social services has never been used, due to a lack of understanding or because the physical aids are not properly suited to their needs.

### Service Delivery Level – Benefits

- 4.9 It was highlighted in the consultations that conventional forms of delivery are, at service delivery, regarded as cost effective. There are, for example, economies of scale to be made by caring for people within institutions where 30 people will require only six staff; Independent Living may well require higher average staffing levels. Block contracts can also be advantageous for certain consumables with costs driven up through individual procurement. A critical mass is also required to sustain some types of services and a movement towards more Independent Living options could endanger their continuation.
- 4.10 In addition, the current system allows local authorities and other service delivery organisations to set budgets and deliver a standard service within that budget. There is a certain anxiety amongst budget holders that Independent Living scenarios could result in an “open ended commitment”, despite the fact that the care budget would still be set and funding packages would be provided within it.
- 4.11 Finally it is worth noting that conventional support mechanisms (such as residential care or home care services) may still be able to provide choice and control for disabled people. Some disabled and older people may need or prefer the security and lack of responsibility that conventional services offer, especially if this is accompanied by the degree of choice and control with which they are comfortable.

### Macro Level – Costs

- 4.12 It is widely acknowledged that traditional institutional living arrangements generally inhibit individuals' ability to work, which clearly has an impact on tax revenues, National Insurance and pension contributions. Within the context of an aging population there is a huge incentive to encourage economic activity amongst all those who are willing and able to work.

- 4.13 The fact that those disabled and older people, who are prevented from working due to the restrictions of their care package, are not contributing to the Exchequer funds is only one part of the problem at macro level. This is magnified by the costs to the Exchequer in state benefits. A report by the Audit Commission in 2005<sup>17</sup> for the DWP pointed out that when a disabled person moves into a job “they save the Exchequer money through reduced benefits and generate money through payment of taxes and national insurance. Their participation in the workforce also makes a contribution to the wealth of their employers and the country as a whole. For example, for the New Deal for Disabled People, the estimate net benefit to the economy is in the region of £400 per job entry”.
- 4.14 A DWP estimate (2005/6) of the average saving for each disabled person who moves into work after participating in the New Deal For Disabled is £6,300 per annum. This comprises £5,200 for Incapacity Benefit (and long-term Income Support), and £1,100 for Housing Benefit and Council Tax Benefit.<sup>18</sup>
- 4.15 The Spring Labour Force Survey (LFS) 2005 shows that only 50% of disabled people were in work, compared with 80.5% of non-disabled people. According to the LFS, there were 2.5 million disabled people out of work and on state benefits, one-third (0.83 million) of whom said that they would like to work. If all of this latter group were enabled to assume employment, the Exchequer saving on state benefit payments would be over £5 billion per annum. This does not include the additional tax revenues which would also be accrued.
- 4.16 Some studies have attempted to quantify the macro level costs

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<sup>17</sup> National Audit Office (2005), Gaining and retaining a job: the Department for work and Pensions’ support for disabled people, Department for Work and Pensions.

<sup>18</sup> These average net savings are based on a cost benefit analysis of those disabled people who have entered employment after being part of the New Deal for Disabled People (NDDP) initiative.

<sup>19</sup> Sainsbury Centre for Mental Health (2003), The economic and social costs of mental illness.

of certain types of disability. For example, in 2003 the Sainsbury Centre for Mental Health<sup>19</sup> estimated that the total annual costs of mental health problems in England were in the region of £77.4 billion. Output losses associated with missed employment opportunities were estimated at £23.1 billion per year, whilst care provided by the NHS, local authorities, private funded services, family and friends, was costed at £12.5 billion. The remaining £41.8 billion was estimated as the human costs of reduced quality of life, including premature mortality. Furthermore, there was an additional cost to the state in benefits for adults with mental health problems; this was estimated at an additional £9.5 billion (ie not included in the £77.4 billion). The Social Exclusion Unit's report in 2004 on Mental Health and Social Exclusion expanded on this analysis and argued that "earlier intervention to keep people in work and maintain social contacts could significantly reduce these costs".

- 4.17 Many stakeholders consulted for this report also highlighted the long-term Exchequer costs incurred through the delivery of conventional support. If a person is in a state of dependency, it is rare for them to be in active employment, able to participate in many leisure pursuits, consume the healthiest food or interact socially. This naturally has a knock on effect on physical and mental health status and, as such, adds to NHS costs of addressing these symptoms. The more complex a person's care needs become, due to lack of early intervention, the higher the cost of the service. Provision of services at the emergency and acute service level is more expensive than simpler, earlier and more tailored support. It is not cost effective to intervene at crisis point; preventative rather than remedial care provides better value for money.
- 4.18 Finally, there are some qualitative costs at macro level, which should not be overlooked. For example, ageism and discrimination against disabled people are both caused and perpetuated by conventional care approaches that do not empower individuals to have choice and control over delivery of their care. These outcomes are, in themselves, costs to society.

## Macro Level – Benefits

- 4.19 Those stakeholders and case study individuals we consulted did not highlight any macro level benefits of the conventional support options for disabled and older people.

## Independent Living Support

### Service Delivery Level – Costs

- 4.20 There are a variety of costs involved with the delivery of Independent Living support options. The transformational costs are likely to be considerable. Most commonly noted were the training and administration costs, for both the statutory and voluntary sector, that a wholesale transition to Independent Living would involve. Support will need to be provided for the workforce and commissioners in delivering a more responsive and demand led service. It is acknowledged, however, that these additional costs would be a one off in order to enhance and refocus public sector infrastructural capacity. There is confidence that these costs would be offset in the medium to long term.
- 4.21 A more continuous cost would be the additional practical, financial and emotional support services that would have to be made available for individuals to enable them to take responsibility for their own care package. Disabled and older people, and their relatives, will require information and education on managing the resources allocated to them and, in some cases, acting as employers. Employing personal assistants and/or purchasing services can be like running a small business. As such, there will be a service cost in ensuring that people are properly equipped to undertake these responsibilities. Independent Living is labour intensive, which is a point which should not be overlooked.
- 4.22 Service delivery costs of implementation are also likely to be high as, presently, resources are substantially tied up in 'bricks and mortar' in the forms of institutional and residential care settings. This factor means that transformational costs for local authorities will be high and could act as a significant disincentive to invest in Independent Living provision.
- 4.23 A key point, made by several consultees is that cost savings are not as likely to be felt at service level as at macro level in the short to medium term. It will be local authorities and the voluntary sector that have to bear set up and running costs for new initiatives, which may result in significant upfront costs. These investments will, in many cases, result in savings for the NHS and the benefit

system but these savings are not transferred to the local authority or the third sector when realised. As such, there could be a net cost at the service delivery level even if at a macroeconomic level savings are realised.

- 4.24 Independent Living options are also subject to more risk, which is a further potential cost at the service delivery level.

#### Service Delivery Level – Benefits

- 4.25 Even though local authorities may be anxious about the inability to tender block contracts for care provision, Independent Living is regarded as delivering better value for money. As people will be commissioning their own carers, to meet with their own specific requirements, they will be able to make more efficient and effective use of resources. It is also likely that they will be far more satisfied with provision and hence councils will have to deal with fewer complaints.
- 4.26 It is expected that direct payments, individual budgets and the introduction of market choice with a more consumerist ethos in care services should result in driving up quality of provision and, therefore, the outcomes for both individuals and employees, resulting in lower turnover. Furthermore, Independent Living options have the potential to significantly reduce administration and infrastructure costs in what is currently a highly bureaucratised sector.
- 4.27 Qualitatively, the provision of more personal levels of care, which has been chosen by the service recipients directly, should bring with it moral benefits at service level. Staff will be delivering serv-

ices which are liberating and emancipating disabled and older people, which in turn could lead to greater levels of job satisfaction for those delivering the service.

### Macro Level – Costs

4.28 It was also noted by several stakeholders that if Independent Living support services are provided in addition to traditional support, there will not necessarily be any cost savings at a macro-economic level. Costs are more likely to be reduced, however, if those with the responsibility for service provision make a conscious decision to divert their priorities and resources towards prevention and tailored services, rather than just providing ad hoc independent living options to supplement current services. They were of the opinion that a 'bolt on' approach is not cost efficient; the whole service structure needs to be re-engineered rather than just undertaking piecemeal changes. They won't be paying twice at least not in a traditional sense so probably best not to put it like that.

### Macro Level – Benefits

4.29 As discussed above, Independent Living supports individuals to be more active in society which may enable them to take up employment and, hence, contribute to tax revenues and National Insurance payments. This, in turn, may allow disabled and older people to contribute in other ways, which were previously not possible for example, spending money within their community, sharing skills and knowledge, volunteering, engaging in public life.

4.30 In addition, whilst there is limited firm evidence on the longer term benefits of independent living, there is increasing belief that those who are supported to live independently make fewer demands

# 5 Conclusions

## Conclusions from the literature review

- 5.1 From the extensive literature review that has been undertaken, the gaps in the availability of cost and benefit data are self-evident. There is, as yet, no systematic comparison of the costs and benefits setting independent living support options against conventional support in the UK. Generally there is very little discussion of quantifiable benefits to the Exchequer or the net social benefits as a result of independent living support; for example, there is an absence of data on the benefits of increased participation in employment and education. Furthermore, whilst many studies have been able to capture some of the immediate benefits of independent living options for individuals, our interrogation of the literature shows that very few have managed to deploy robust methods to value benefits quantitatively. Cost data was more plentiful at service delivery level, compared to individual and macro-economic level, but again evidence on benefits is sparse.
- 5.2 Partly responsible for the lack of robust cost and benefit data at individual, service delivery or macro-economic level, is the relative recency of the Independent Living agenda both in research and implementation. Many independent living options are very new or still in pilot form, with little emerging evidence on costs and benefits. This precludes a longitudinal analysis, which would illustrate the long-term cost and benefits impacts. In the long term, the costs of any investment or diversion of resources to independent living support may be offset by the benefits. The literature makes strong references to the likelihood of long-term benefits accruing to the Exchequer and society in the form of reduced reliance on health and social care services and the reduction in overall dependency

on informal support. It is also too early to assess key qualitative outcomes such as inclusive social relationships and community engagement. The expected dynamic and long-term outcomes cannot be addressed at this point, meaning that some gaps are inevitable.

- 5.3 A further issue that this review has identified is the methodological difficulty in attributing values to qualitative costs and benefits. Despite some academic progress in attempting to overcome this issue, there are still fundamental problems with quantifying benefits, in particular, when they relate to improvements in quality of life or physical and emotional well-being.
- 5.4 Having made these caveats, the literature does enable us to draw some preliminary conclusions. Published material to date indicates that the delivery of independent living support to disabled people and to older people is more cost effective, or at least no more expensive, than traditional care provision.
- 5.5 There was particular evidence at service level, with several evaluations highlighting the higher costs of NHS and institutional provision compared to Independent Support mechanisms such as Direct Payments. A variety of reasons were put forward in the literature to substantiate these findings, such as the higher administrative overheads for the conventional support services. The small amount of data that did exist at macro level also indicated that considerable cost savings could accrue to the Exchequer, in increased tax revenues and reduced benefits payments, from investing in independent living support.
- 5.6 Moreover, despite difficulties in valuation, there is also extensive qualitative evidence on independent living benefits and the improvements delivered in terms of physical and emotional well-being. The literature documented particular enhancements in health status, satisfaction, participation in society, motivation, self-esteem and greater degrees of choice to mention but a few. These benefits significantly outweigh the benefits that were mentioned for conventional forms of support.

## Conclusions from the case studies and consultations

- 5.7 The five case studies that were undertaken as part of the review

enabled us to identify and analyse some more up-to-date findings from a variety of independent living mechanisms that are currently being implemented. The messages that emerged largely corroborated the literature review findings.

5.8 As found in the published material, independent living options often revealed themselves to be more cost effective, to varying degrees, than conventional systems of support. For example, evidence from the case studies indicated that:

- It costs local education authorities considerably more to send young disabled people to out-of-authority residential schools rather than facilitating their further education within their community.
- The overall costs of enabling parents with learning disabilities to assume custodial care of their child, through the use of advocacy and support services, are less than the costs involved in putting the child through the adoption process.
- The costs of provision of advocacy support to help disabled individuals remain in employment are considerably less than the financial gains made by individuals through salary retention and their application for other entitlements. These advocacy support costs are also significantly outweighed by the costs that would be incurred at Exchequer level if the service were not in place – i.e. if individuals became unemployed, benefit payments would be required and there would also be a loss in tax revenues.
- Forecast savings from the Independent Living service for older people in Dorset are likely to be worth more than double the initial investment in the partnership project.

5.9 The evidence from one of the case studies, which looked at provision for disabled people in residential institutions did slightly go against the trend. It emerged that conventional support costs were marginally lower than provision of an independent living option. This would seem to reinforce the suggestion, made by some consultees, that institutional provision, especially for those with complex needs, requires a lower staff ratio than would be needed outside a residential setting. The difference in costs, however, was marginal in the two cases that we reviewed, and may

reflect in part the different cost of service provision in the two local authorities. In addition, the disabled people interviewed stressed that the qualitative benefits, in terms of enhanced freedom and control over their life, more than offset the minimal extra costs at an individual level.

- 5.10 The case studies and strategic consultations, served to corroborate the already extensive evidence on qualitative benefits of independent living outcomes for the individual. Those interviewees in receipt of conventional support commented on the absence of choice and control, restricted access to social and labour market participation, emotional distress, over-reliance on friends and family and the general culture of dependency it breeds. In stark contrast, those experiencing independent living provision spoke of the equality that they felt, improved social, recreational and professional opportunities, enhanced confidence and mental health, freedom with which to make life decisions, the flexibility in provision and its sensitivity to individual circumstances.
- 5.11 This last point reiterates the arguments put forward in the literature review – that in assessments of independent living support, despite the difficulties with valuation, qualitative benefits are a crucial component to include within the analysis.

### Service and macro-economic conclusions

- 5.12 A particularly useful output from the case studies and strategic consultations was the additional information on costs and ben-

efits at service delivery and macro level, which expanded on the messages from the literature. Several consultees made references to the costs associated with conventional support due to inefficiencies involved in delivery. Inflexible block contracts, inflated agency charges and an assessment system which can result in individuals receiving over and above their care requirements were all highlighted as wastage. Equally, however, there were some acknowledged service level benefits. Not least was the economies of scale argument and the view that existing service provision actually serves the needs of many individuals who do not want the responsibility of directing their own care and, instead, prefer the security of decisions being made for them.

- 5.13 Most telling was the evidence uncovered on the macro-economic costs incurred under conventional forms of care delivery. It was identified by strategic consultees and recipients themselves that conventional services act as a substantial barrier to undertaking paid employment. Preventing disabled and older people from working has a significant impact on tax revenues and incurs considerable cost to the Exchequer in the payment of state benefits. In addition, it has been identified that far higher costs are incurred by health and social services when they are required to provide remedial (conventional) rather than preventative (independent living) care.
- 5.14 Stakeholders also commented extensively on the costs and benefits under independent living support options. It was widely acknowledged that, particularly in the short term, implementation of independent living would involve considerable transformational costs in order to finance workforce development and administration of a new system. The fact that a large proportion of provider capital is tied up in the institutional buildings would also add to the transition costs. Whilst these two issues may require a one-off investment, provision of adequate emotional and practical support to individuals, so that they properly equipped to manage their own care, would be more enduring. In addition, a particularly salient point raised in the consultations, was that any savings are more likely to be felt by emergency and acute care services in the long term, rather than local authorities and providers themselves, despite the fact that the latter groups are required to make the upfront investment.
- 5.15 Equally, however, there are benefits at service delivery level, which

are expected to manifest themselves in the long term. Through increased personalisation of services, care provision is forecast to be of better quality, more efficient and enhanced value for money.

- 5.16 Interestingly, as opposed to the case for conventional support, case study and consultation evidence suggests that, on a macro-economic level, independent living is a cost effective option. This conclusion is premised on the assumption that independent living will permit far more disabled people to contribute tax and national insurance payments and that the benefits bill will also be reduced. Moreover, in the long term, the demands on other public services, particularly health service, is expected to be considerably less.

### Barriers

- 5.17 Aside from the upfront investment costs, several other barriers to the wider implementation of independent living were identified during the research. A number of interviewees highlighted that there is an inherent resistance towards change within the social care sector. As presently configured, this sector employs vast numbers of people; provision of care to disabled people is their 'bread and butter' service and there is some reluctance to let go of this. By relinquishing commissioning responsibility service providers are, in effect, sacrificing their power and control, a departure that some may find difficult to accept. Amongst care managers and service deliverers, therefore, there is somewhat of a vested interest and perverse incentive in keeping disabled people 'passive' and dependent so that the status quo position in terms of institutions, processes and workforce skills can be maintained. It was suggested by the interviewees that there is also evidence, of 'silo thinking' and comments were made that boundary management could act as a constraint on the full implementation of independent living. Department budget holders are reportedly nervous about organisational change and pooling resources.
- 5.18 Language and cultural issues will also need to be overcome if independent living is to be properly implemented. This information about independent living options needs to be presented in accessible and comprehensible formats to potential service recipients and their families. This can particularly be the case for older people who could be reluctant to participate in decision making if the new ways of working are not properly explained.

A potential barrier to take up of services, mentioned by several consultees, was getting information to people in a timely manner. It is often the case that disabled people and older people are not made aware of the independent living options until they have reached 'crisis point' and are in need of emergency provision. To be of optimum use to both the individual and society, more timely and widespread dissemination of information needs to be considered.

## Overall conclusions

- 5.19 The evidence from the literature review, case studies and consultations enables us to draw three broad conclusions about the costs and benefits of independent living options.
- 5.20 At an individual level there is substantial qualitative evidence, from both the literature review and the case study research, suggesting that IL provides significantly more benefits than conventional forms of service provision. Some of the case studies undertaken as part of this research also indicated that IL can also be cost effective for the individual recipients.
- 5.21 At service delivery level several published evaluations that were identified in the literature highlighted the reduced costs involved in the delivery of Independent Support mechanisms. Consultations and the case studies undertaken reinforced this view, by highlighting the inherent inefficiencies involved in traditional care provision. It was also pointed out, however, that there would be considerable transformational costs involved in rolling out IL more widely. It is largely expected that these upfront costs will be offset in savings, at both service delivery and macro level, in the long term, suggesting, therefore, the need to accept an 'invest to save' approach.
- 5.22 The published material at macro-economic level on the costs and benefits of independent living is relatively sparse. However, the literature does highlight that there are significant costs for the Exchequer in not addressing barriers faced by disabled people. Evidence from the case studies and consultations corroborates and strengthens this view, showing that investment in independent living would result in sizeable Exchequer long-term cost savings, due to the increase in tax revenues, a reduced state benefits bill

and less pressure on health and acute social care services.

## The wider policy implications

- 5.23 There are significant gaps in the level and amount of evidence evaluating the costs and benefits of independent living, compared to conventional provision. This is due in part to the recent implementation of IL. A more systematic cost benefit analysis of the impacts at individual, service delivery and macro-economic level needs to be conducted in order to subject IL options to a robust and longitudinal analysis and to attempt to quantify some of the frequently mentioned qualitative benefits. This research will also need to compare over time the impact of both IL and conventional provision.
- 5.24 Investment in IL will not necessarily result in optimum cost savings if a 'bolt-on' or piecemeal approach to implementation is taken. Instead, investment in long-term sustainable projects, rather than small pilots is more likely to realise the potential benefits and economies of scale.
- 5.25 Cross Government collaboration between individual departments, particularly DH, DWP and DCLG, will be central to the development of a strategic view on the aggregate savings that can be made through the implementation of independent living.
- 5.26 As highlighted by the Strategy Unit's report<sup>20</sup> in 2005, there is 'a failure to see expenditure on independent living as a form of social and economic investment'. Instead, traditionally, disability benefits have been viewed as a transfer or redistributive payment – i.e. not intended to effect any sort of economic gain. This narrow perspective needs to be refreshed to permit a wider appreciation of the macro benefits from delivering independent living and highlight the economic case for investment in IL support mechanisms.

- 5.27 Finally, it is worth noting that implementation of independent living is likely to result in long-term savings at service delivery level, but that larger cost benefits will accrue at the level of the Exchequer, due to reduced pressure on health services and improved tax revenues. As such, whilst Local Authorities will be required to invest, it will be the Exchequer that reaps more of the savings. It will be necessary to investigate how to transfer some of the benefits back to service providers in order to incentivise them to embrace wholesale IL implementation.

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<sup>20</sup> PMSU (2005), Improving the life chances of disabled people.



# Annex A: Search terms for the literature

- Independent living:
  - social benefits
  - economic benefits
  - physical health benefits
  - mental health benefits
  - well-being
  - employment support
- Disabled people:
  - choice/control
  - social inclusion/exclusion
- Older people/BME groups:
  - independence
  - choice/control
  - social inclusion/exclusion
  - active citizenship
- Costs, benefits of:

- personal care/ assistance
- nursing care
- communication/advocacy
- learning support
- ‘talking treatments’
- aids, equipment, adaptations
- residential, long-term care
- self-directed support
- direct payments
- Cost-effectiveness of interventions
- Welfare benefits savings and costs

## Annex B: Literature review sources

- ISI Web of Science consists of the Science Citation Index, Social Sciences Citation Index, and Arts & Humanities Citation Index. They provide bibliographic details of articles from thousands of academic journals from 1981 onwards. Abstracts are available for many articles. This source was used to derive and identify a list of articles that were relevant for the study, using key search terms.
- JSTOR is a digital archive collection of core scholarly journals, with multi-disciplinary collections within Arts and Sciences. This database was used to download and access the articles identified via the citation index as well as other articles.
- International websites – several institutional and government websites, as well as those directly linked to independent living policy and philosophy.
- Websites of DWP counterparts in the USA, Canada, Australia.
- UN Enable (UN policy on disability, <http://www.un.org/esa/socdev/enable/unpgm.htm>)
- OECD ([http://www.oecd.org/document/61,0,2340,en\\_2649\\_33929\\_35490493\\_1\\_1\\_1\\_1,00.html](http://www.oecd.org/document/61,0,2340,en_2649_33929_35490493_1_1_1_1,00.html))
- EU Disability Strategy Website [http://ec.europa.eu/employment\\_social/disability/strategy\\_en.html](http://ec.europa.eu/employment_social/disability/strategy_en.html))
- The Canadian Association of Independent Living centres ([http://www.cailc.ca/CAILC/graphic/home\\_e.html](http://www.cailc.ca/CAILC/graphic/home_e.html))

- Independent Living Centres in Australia (<http://www.ilcaustralia.org/default.asp>)
- Physical Disability Council of Australia (<http://www.pdca.org.au/cgi-bin/pdca/static/costofdisability.html>)
- Websites of research institutions – Disability Research Institute USA, National Center for the Dissemination of Disability Research USA, The Urban Institute USA, National Centre for Social Research UK, Disability Research Unit and Disability Archive at University of Leeds, NCIL publications UK, Joseph Rowntree Foundation UK, King’s College London – Centre for the Economics of Mental Health, King’s Fund UK, Policy Studies Institute UK, London School of Economics (SAGE and CASE).
- DH, DWP, DfES and DTI research reports and publications, including ‘grey’ literature such as emerging findings from pilot initiatives or programmes. These include the In Control project, the Prevention and Older People pilots, and the Individual Budgets pilots.
- Iterative search – Based on the bibliography of some of the most cited articles, individual electronic searches were carried out in specific journals.

# Annex C: Literature review template

The template document below shows the headings under which we collected information during the literature review.

Title, Author etc
Origin of research/relevance to the UK
Broad purpose/summary of content
Definitions
Methodology
Findings
Own evaluation of research
Major Sources/Other Papers to Investigate



# Annex D: Case study and consultation discussion guides

The following four discussion guides were used for the all face-to-face and telephone interviews.

## Strategic Stakeholder Discussion Guide

### Introduction

SQW has been commissioned by the Office for Disability Issues to conduct research for the first stage of the Independent Living Review. The research includes a costs and benefits review of investment in independent living support and some case studies to illustrate different scenarios. We are contacting you as an expert in this area to assist us by discussing your views of the key issues that a cost benefit analysis needs to address. We would like to add that all information disclosed during the interview will be treated as confidential unless you confirm that we may cite the information in our report.

## Topics for discussion

### Background

1. What do you understand by the term independent living?
2. Please could you describe your specific areas of interest/research regarding investment in independent living support for disabled people?

### The Present System

3. What costs are involved in delivering the current system?
  - Individual costs (informal care from family members, increased independence public services, loss of wages as a result of not working or working less, barriers to social participation, increased dissatisfaction with quality of life).
  - Service delivery costs (resource costs; recruitment costs; actual costs of delivering package; any additional personnel/wage costs of liaising with partners, community and beneficiaries, non-measurables such as time and effort spent administering the system, possible dissatisfaction with existing structures).
  - Macro level costs (aggregate costs of welfare/incapacity/housing benefits, wastage due to duplication of services, any foregone tax revenues from people providing informal care, future costs and demand, worsened social exclusions indicators).
4. Can you quantify any of the costs that you have specified?
5. What are the benefits of the present system?
  - Individual level benefits (wage gains from employment; costs savings for individual and family; satisfaction with public services).
  - Service delivery benefits (economies of scale cost savings – sharing personnel/training; levels of confidence in professional service delivery; protection from risk due to regulation).
  - Macro level benefits (wage gains due to increased labour participation; aggregate costs savings ; economies of scale across interventions; control over resources).
6. Can you quantify any of the costs that you have specified?

## Independent Living

7. In your view what constitute some of the key benefits of investment in independent living support?
  - Individual level benefits (wage gains from employment; costs savings for individual and family; reduced dependency; increased accessibility to physical infrastructure; more personalised support; increased public service satisfaction; enhanced confidence; increased social participation; skills development; improved physical/mental health).
  - Service delivery benefits (cost savings due to reduced reliance on care workers; reduced reliance on institutional care; reduced recruitment and retention and other central infrastructure costs due to more user control; improved levels of satisfaction with system).
  - Macro level benefits (wage gains due to increased labour participation; aggregate costs savings due to reduced informal care; savings in health and social care interventions; sustainability of preferred support arrangements).
8. Can you quantify any of the benefits that you have specified? What evidence of these benefits can you provide?
9. Are there any costs involved in with provision of independent living?
  - Costs to the individual (responsibility for managing personal care; self-training, education, admin, wage losses incurred through time dedicated to managing personal assistance).
  - Service delivery costs (resource and start up costs; recruitment costs; actual costs of assistance package; any additional personnel/wage costs of liaising with partners, community and beneficiaries, non-measurables such as time and effort spent administering a new system, possible dissatisfaction with new structures).
  - Macro level costs (aggregate costs of welfare/incapacity/housing benefits, wastage due to duplication of services, any foregone tax revenues from people providing informal care, future costs and demand).
10. Can you quantify any of the costs that you have specified?

### Concluding thoughts

11. What in your view are the main barriers to developing an independent living strategy?
12. Are there any recent publications/working papers you feel we should include in the literature review component of our research, specifically on costs and benefits, and that we might not be aware of – e.g. research in progress?

SQW would like to thank you for your support and contribution to this research.

## Service provider/support work discussion guide

### Introduction

SQW has been commissioned by the Office for Disability Issues to conduct research for the first stage of the Independent Living Review. The research includes a costs and benefits review of investment in independent living support and some case studies to illustrate different scenarios. One of the case studies concerns [insert case study name]. We are contacting you due to your involvement and experience in this area and hoping you will be able to assist us by sharing your views of the key issues that a cost benefit analysis needs to address. We would like to add that all information disclosed during the interview will be treated as confidential unless you confirm that we may cite the information in our report.

### Topics for discussion

#### Background

1. Please could you describe your area of work and responsibilities? Do you provide services, support or assistance to disabled people? What is the nature of this support?
2. We are interested in exploring the issue of support for independent living for disabled people. What do you understand by this term?
3. Drawing on your experience, can you give any examples of the barriers that may prevent a disabled person from living independently?
4. What types of support do you think are necessary to enable [insert case study name] to live independently?
5. What experiences do you have of providing independent living support? Or does your work facilitate independent living? If so, please give examples of the way in which it does.

### The Present System

6. What costs are involved in delivering the current system?
  - Individual costs (informal care from family members, increased independence public services, loss of wages as a result of not working or working less, barriers to social participation, increased dissatisfaction with quality of life).
  - Service delivery costs (resource costs; recruitment costs; actual costs of delivering package; any additional personnel/wage costs of liaising with partners, community and beneficiaries, non-measurables such as time and effort spent administering the system, possible dissatisfaction with existing structures).
  - Macro level costs (aggregate costs of welfare/incapacity/housing benefits, wastage due to duplication of services, any foregone tax revenues from people providing informal care, future costs and demand, worsened social exclusions indicators).
7. Can you quantify any of the costs that you have specified?
8. What are the benefits of the present system?
  - Individual level benefits (wage gains from employment; costs savings for individual and family; satisfaction with public services).
  - Service delivery benefits (economies of scale cost savings – sharing personnel/training; levels of confidence in professional service delivery; protection from risk due to regulation).
  - Macro level benefits (wage gains due to increased labour participation; aggregate costs savings ; economies of scale across interventions; control over resources).
9. Can you quantify any of the costs that you have specified?

## Independent Living

10. In your view what constitute some of the key benefits of investment in independent living support?
  - Individual level benefits (wage gains from employment; costs savings for individual and family; reduced dependency; increased accessibility to physical infrastructure; more personalised support; increased public service satisfaction; enhanced confidence; increased social participation; skills development; improved physical/mental health).
  - Service delivery benefits (cost savings due to reduced reliance on care workers; reduced reliance on institutional care; reduced recruitment and retention and other central infrastructure costs due to more user control; improved levels of satisfaction with system).
  - Macro level benefits (wage gains due to increased labour participation; aggregate costs savings due to reduced informal care; savings in health and social care interventions; sustainability of preferred support arrangements).
11. Can you quantify any of the benefits that you have specified? What evidence of these benefits can you provide?
12. Are there any costs involved in with provision of independent living?
  - Costs to the individual (responsibility for managing personal care; self-training, education, admin, wage losses incurred through time dedicated to managing personal assistance).
  - Service delivery costs (resource and start up costs; recruitment costs; actual costs of assistance package; any additional personnel/wage costs of liaising with partners, community and beneficiaries, non-measurables such as time and effort spent administering a new system, possible dissatisfaction with new structures).
  - Macro level costs (aggregate costs of welfare/incapacity/housing benefits, wastage due to duplication of services, any foregone tax revenues from people providing informal care, future costs and demand).
13. Can you quantify any of the costs that you have specified?

### Concluding thoughts

14. We have discussed both quantifiable and non-quantifiable costs and benefits to individuals. How much importance do you think should be attached to non-quantifiable costs and benefits and why?
15. What do you see as the most effective mechanisms by which to involve disabled people in identifying their support needs and the ways in which to address those needs addressed? Are there any difficulties in putting these approaches into practice?

SQW would like to thank you for your support and contribution to this research.

### Individuals' Discussion Guide

(not in receipt of IL provision)

## Introduction

SQW has been commissioned by the Office for Disability Issues to conduct research for the first stage of the Independent Living Review. The research includes a costs and benefits review of investment in independent living support and some case studies to illustrate different scenarios. One of the case studies concerns [insert case study name]. We are contacting you in the hope that you will be able to assist us by sharing your views and experiences of support provided. We would like to add that all information disclosed during the interview will be treated as confidential unless you confirm that we may cite the information in our report.

## Topics for discussion

### Background

1. Please could you tell me a bit about yourself and your current situation? [Ask about housing, family, and work]
2. Please could you describe what kind of support services that you currently receive? (social services/family support/user groups support)
3. Do you have any current source of financial support – e.g. benefits, income from employment etc?
4. We are interested in exploring the issue of support for independent living for disabled people. Can you describe what the term independent living means to you?
5. Do the support services that you receive enable you to live independently?

### Costs

6. Drawing on your experiences under the current support system what costs are involved to you as an individual?
  - Are there any costs incurred to family members for informal care?
  - Do you think that there are costs incurred due to an increased dependence on public services?
  - Have you experienced a loss of wages from not working or working fewer hours than you would be able if you had more, or different, kinds of support?
  - Do you find that there are any barriers to social participation?
7. Can you quantify the costs that you have specified?
8. In your view what would be the impact on you as an individual if you were to receive more support to live independently:
  - Additional time or expense in managing own personal assistance (self training/education in managing/budgeting)?
  - Wage losses due to time spent away from work in managing your own support?
  - Any other costs?

### Benefits

9. In your experience what constitute some of the key benefits of your existing system of support (cost savings to individual and family; quality of life; participation in social life)?
10. What additional benefits do you think support to live independently would give you and what form might this support take?
  - Do you envisage wage gains, as a result of independent living support, which would enable you to return to work or work more hours?
  - Would there be any housing, transport or health care savings?
  - Would it reduce your dependency on family members?

- Would you be more satisfied and confident with the services you receive if you had more choice and control over what is provided?
  - Do you think that independent living support would remove barriers to social participation/ help you to engage with service providers?
  - Would it improve your quality of life? If so how?
  - Do you think independent living support would give you more choice and control over your life?
11. Can you quantify any of the benefits that you have specified in terms of cost savings?

### Concluding thoughts

12. Drawing on your experience, can you give any examples of the barriers that may prevent a disabled person from living independently?
13. What types of support do you think are necessary to enable [insert case study name] to live independently?
14. What do you see as the most effective mechanisms by which to involve disabled people in identifying their support needs and the ways in which to address those needs addressed? Are there any difficulties in putting these approaches into practice?

SQW would like to thank you for your support and contribution to this research.

## Individuals' Discussion Guide (in receipt of IL support)

### Introduction

SQW has been commissioned by the Office for Disability Issues to conduct research for the first stage of the Independent Living Review. The research includes a costs and benefits review of investment in independent living support and some case studies to illustrate different scenarios. One of the case studies concerns [insert case study name]. We are contacting you in the hope that you will be able to assist us by sharing your views and experiences of support provided. We would like to add that all information disclosed during the interview will be treated as confidential unless you confirm that we may cite the information in our report.

### Topics for discussion

#### Background

1. Please could you tell me a bit about yourself and your current situation? [Ask about housing, family, and work]
2. Please could you describe what kind of support services that you currently receive? (social services/family support/user groups support)
3. Do you have any current source of financial support – e.g. benefits, income from employment etc?
4. We are interested in exploring the issue of support for independent living for disabled people. Can you describe what the term independent living means to you?
5. Do the support services that you receive enable you to live independently?

## Benefits

6. In your experience what constitute some of the key benefits of independent living support?
  - Have you experienced any wage gains as a result of the independent living support you have received?
  - Has it enabled any housing, transport or health care savings?
  - Has your dependency on family members decreased and have there been savings as a result?
  - Are you more satisfied with service provision under independent living support?
  - Do you find that independent living support has removed barriers to social participation/ helped you to engage with service providers?
  - Has it improved your quality of life? How?
  - In what areas of your life do you feel you now have more choice and/or control? How does this affect your confidence?
  - Are there any future benefits that you envisage as the independent living system becomes more established?
7. Can you quantify any of the benefits that you have specified?

## Costs

8. Drawing on your experiences what costs are involved with the independent living?
  - Are there any additional costs that you incur in managing your own personal assistance (self training/education in managing/ budgeting)?
  - Have you experienced wage losses due to time spent away from work in managing your own support?
  - Are there any administration costs that you have to bear?
  - Are there any other costs that you incur?
9. Can you quantify the costs that you have specified?

10. What costs do you think you would incur if you did not receive support to live independently?
  - Would there be costs incurred to family members for informal care?
  - Without the support you currently receive would you be less able to work, or only be able to work fewer hours? Can you give an idea of what that would mean in terms of lost wages?
  - Without the support to live independently, what would be the effect on your ability to take part in social activities?

### Concluding thoughts

11. Drawing on your experience, can you give any examples of the barriers that may prevent a disabled person from living independently?
12. What types of support do you think are important to enable [insert case study name] to live independently?
13. What do you see as the most effective mechanisms by which to involve disabled people in identifying their support needs and the ways in which to address those needs addressed? Are there any difficulties in putting these approaches into practice?

SQW would like to thank you for your support and contribution to this research.

## Annex E: Disabled parents case study – detailed costs

The following tables detail the costs for the two different scenarios involving disabled parents and care of their children. The costs indicated below would be incurred over a time period of several years. We note that in this case study, costs given are at current prices, and have not been discounted over time.

### Conventional support - Fostering, followed by adoption

Cost	Total cost	Assumptions (includes amount; frequency/duration; purpose)
Pre-birth assessment by Children's Team	£160	This would cost the same under any of the scenarios, regardless of the outcome <ul style="list-style-type: none"> <li>8 hours of input @ £20 per hour</li> </ul>
<b>Phase A: Fostering – 1 year</b>		
Ongoing social hour worker for child	£2,080	<ul style="list-style-type: none"> <li>2 hours per week @ £20 per</li> </ul>
Family support worker hour	£390	<ul style="list-style-type: none"> <li>For first three months only (13 weeks)</li> <li>2 hours per week @ £15 per</li> </ul>
Supervision through days Children's Team with worker (during visits) all year	£10,400	<ul style="list-style-type: none"> <li>£20 per hour</li> <li>2 hours of support per day, 5 per week for contact sessions social worker or support worker through Children's Team</li> </ul>

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 Conventional support - Fostering, followed by adoption (continued)
 

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Cost	Total cost	Assumptions (includes amount; frequency/duration; purpose)
Quarterly review by Children's Team	£120	<ul style="list-style-type: none"> <li>1.5 hours, 4 times per year @ £20 per hour</li> </ul>
Payments to foster parents	£10,192	<ul style="list-style-type: none"> <li>Weekly payment - £196 / week</li> <li>52 week period</li> </ul>
<b>Phase B: Adoption</b>		
Legal costs	£50,000	Including expert witnesses. Assumes relatively straightforward case.
Independent guardian for child (through CAFCAS)	£40,000	
Independent reviewing officer		
Additional support? 2 social workers/ Family support workers/ Health worker		
Ongoing reviews by Children's Team	£240	<ul style="list-style-type: none"> <li>1.5 hours each time @ £20 per hour</li> <li>Every 3 months for nominal (in this instance, we</li> </ul>
period assume 2 years)		
Supervision on visits post-adoption?		
<b>Total:</b>	<b>£113,582</b>	

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## Notes

- Foster care with another family member or friend - payments would be around £84 per week (including £56 basic and £28 expenses components). Through local authority foster-carers, payments would be around £196 (including boarding, expenses and recompense). Agency foster carers can cost between £250 per week and up to £1000 per week, for difficult teenagers.
- Excludes legal aid provided to parents

- Excludes adoption allowance

### Independent Living support - Fostering, followed by parents keeping child

This assumes a 'worst case' (difficult) scenario.

Cost	Total cost	Assumptions (includes amount; frequency/duration; purpose)
Pre-birth assessment by Children's Team	£160	This would cost the same under any of the scenarios, regardless of the outcome
Pre-birth support of	£3,250	<ul style="list-style-type: none"> <li>• 8 hours of input @ £20 per hour</li> <li>• £25 per hour</li> <li>• 2 hours per day, 5 days per week</li> <li>• 13 weeks (3 months)</li> </ul>
<b>Phase A: Fostering – 1 year</b>		
Ongoing social hour worker for child	£2,080	<ul style="list-style-type: none"> <li>• 2 hours per week @ £20 per</li> </ul>
Family support worker	£390	<ul style="list-style-type: none"> <li>• For first three months only (13 weeks)</li> <li>• 2 hours per week @ £15 per</li> </ul>
hour		
Supervision through days Children's Team with worker (during visits) all year	£10,400	<ul style="list-style-type: none"> <li>• £20 per hour</li> <li>• 2 hours of support per day, 5 per week for contact sessions social worker or support worker through Children's Team</li> </ul>
3 months of Social joint supervision weeks) to with Adult Social Services	£2,600	<ul style="list-style-type: none"> <li>• Joint supervision with Adult Services in final stages (13 ensure input from both services</li> <li>• £20/hour</li> <li>• 2 hours of support per day, 5 per week</li> </ul>
days		
Quarterly review by Children's Team	£120	<ul style="list-style-type: none"> <li>• 1.5 hours, 4 times per year @ £20 per hour</li> </ul>
Payments to foster parents	£10,192	<ul style="list-style-type: none"> <li>• Weekly payment - £196 / week</li> <li>• 52 week period</li> </ul>
Advocacy worker	£14,500	<ul style="list-style-type: none"> <li>• £25 per hour</li> </ul>

support	<ul style="list-style-type: none"> <li>• TOTAL: 580 hours</li> <li>• 10 hours per week for 52 weeks</li> <li>• PLUS: 1 day Court appearance, once every 12 weeks; + ½ group meetings from social every six weeks = 60 hours</li> </ul>
day core services	

Continued

Independent Living support - Fostering, followed by parents keeping child (continued)

Cost	Total cost	Assumptions (includes amount; frequency/duration; purpose)
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**Phase B: Residential Assessment (Leeds) – 3 month period**

Assessment both people). Still ongoing family to buy	£20,400	<ul style="list-style-type: none"> <li>• £1700 per week centre costs</li> <li>• Costs include parents and child (i.e. 3 recipients of benefits, so responsibility of food etc.</li> </ul>
Adult Social Services support costs during residential	£840	<ul style="list-style-type: none"> <li>• 1* 5-hour visit twice per month @ £20/hour</li> <li>• £40 for petrol/car costs per visit</li> </ul>
Children’s social worker visits during residential	£960	<ul style="list-style-type: none"> <li>• 16 hours per month @ £20 per hour</li> </ul>
Advocate visits during residential month	£1,500	<ul style="list-style-type: none"> <li>• £25 / hour</li> <li>• 1*day visit per week for first</li> <li>• 1* day visit per fortnight for next two months</li> <li>• TOTAL: 8 days = 60 hours</li> </ul>

**Phase C: Intensive support at home**

Children and Family support worker times	£2,730	<ul style="list-style-type: none"> <li>• 2 hours per visit at the house @ £15 per hour</li> <li>• 3 month (13 week) period – 3 weekly (£1,170)</li> <li>• 6 month (26 week) period – 2 weekly (£1,560)</li> </ul>
Adult services worker period, (monitoring and assessment)	£1,360	<ul style="list-style-type: none"> <li>• £20/hour</li> <li>• 2 hours per week - 8 week for monitoring and assessment (£320)</li> <li>• 1 hour per week - 52 week</li> </ul>

period, assessment			for monitoring and (£1040)
Adult services support worker period	£1,140	<ul style="list-style-type: none"> <li>• £15 per hour</li> <li>• 3 hours per week – 8 week (£360)</li> <li>• 1 hour per week – 52 week (£780)</li> </ul>	

Continued

### Independent Living support - Fostering, followed by parents keeping child (continued)

Cost	Total cost	Assumptions (includes amount; frequency/duration; purpose)
Advocate worker visits period	£2,000	<ul style="list-style-type: none"> <li>• £25 / hour</li> <li>• 10 hours per week – 8 week</li> </ul>
Advocate worker (mostly office- period based)	£10,400	<ul style="list-style-type: none"> <li>• £25 / hour</li> <li>• 8 hours per week – 52 week</li> </ul>
Support worker from independent agency  period	£2,912	<p>This level of support would be likely to reduce and in this case study was withdrawn as it was no longer needed after 12 months.</p> <ul style="list-style-type: none"> <li>• £14/hour</li> <li>• 4 hours per week – 52 week</li> </ul>

### Phase D: Lower intensity support at home

Children and Family support worker  indefinitely goes to (£420)	£1,440	<ul style="list-style-type: none"> <li>• 2 hours per visit at the house @ £15 per hour</li> <li>• 6 months – 1x weekly (£780)</li> <li>• 4 months – fortnightly (£240)</li> <li>• Then, once per month, (say 14 months, until child nursery at 4 years old)</li> </ul>
Adult services worker (monitoring and assessment)	£4,640	<p>Includes occasional meetings and phone calls</p> <ul style="list-style-type: none"> <li>• £20 per hour</li> <li>• 8 hours per month, indefinitely</li> </ul>



## References

ACE and Mental Health Foundation (2004) Literature & Policy Review for the Joint Inquiry into mental health and well being in later life.

Altman, B.M. et al. (1999) The Case of Disability in the Family: Impact on Health Care Utilization and Expenditures for Nondisabled Members, *The Millbank Quarterly*, Vol. 77, No.1, pp. 39-75.

Arthur, S. et al. (2004) Making the Transition: Addressing Barriers in Services for Disabled People: National Centre for Social Research.

Askheim, P.O. (2000) 'Personal assistance—direct payments or alternative public service. Does it matter for the promotion of user control?', *Disability & Society*, Norway, Vol. 20, No. 3, pp. 247–260.

Astin, J. et al. (2005) 'Intellectual disability, challenging behaviour and cost in care accommodation: what are the links?' *Health & Social Care in the Community*, Vol. 13, No. 4, pp. 297-306.

Atkins, L. et al. (2003) 'Formal and informal care for people with dementia: variations in costs over time', *Ageing & Society*, Vol. 23, pp. 303–326.

Bamford, C. et al. (1998) 'Mental and physical frailty in older people: the costs and benefits of informal care', RIS MRC CFAS (Resource Implications Study of Medical Research Council Cognitive Function and Ageing Study), *Ageing and Society*, Vol. 18, pp. 317-354.

Barnes, C. and Mercer, G. (2005) Disability, work, and welfare challenging the social exclusion of disabled people, USA.

Bell, D.N.F. (2006) Estimating the cost of free home care for disabled people in Wales.

Bell, D. and Bowes, A. (2006), Financial Care Models in Scotland and the

UK: Joseph Rowntree Foundation.

Berkowitz and Johnson (1970), Towards an Economics of Disability: A Magnitude and Structure of Medical Costs. *The Journal of Human Resources*, Vol. 5, No.3.

Berthoud, R. (1998), Disability Benefits: Joseph Rowntree Foundation.

Bethell, J. and Harrison, M. (2003), An evaluation of a young disabled people's peer mentoring/support project: Joseph Rowntree Foundation.

Bignall, T. and Jabeer, B. (2000), The views of young black disabled people on independent living: Joseph Rowntree Foundation.

Bignall, T. et al. (2000) Directing support: report from a workshop on direct payments and black and minority ethnic disabled people.

Bland, R. (1999) 'Independence, privacy and risk: two contrasting approaches to residential care for older people', *Ageing and Society*, Vol. 19, pp. 539-560.

Boyce, S. and Stainton, T. (2004) 'I have got my life back': users' experience of direct payments', *Disability & Society*, Vol. 19, No. 5, pp. 443-454.

Brandon, D. et al. (2000) 'Making Direct Payments a Choice: A Report on the Research Findings' *Disability & Society*, Vol. 15, No. 1, pp. 99-113.

Burchardt, T (2000) Enduring economic exclusion: disabled people, income and work.

Burchardt, T. (2003) Being and becoming: Social exclusion and the onset of disability: LSE.

Burchardt and Zaidi (2003), Comparing incomes when needs differ: Equivalisation for the extra costs of disability in the UK, CASE Paper 64.

Burge, P. et al. (2006), Valuing PSS outputs and quality changes, PSSRU Discussion Paper 2356/3, Personal Social Services Research Unit, University of Kent.

Cambridge, P. et al. (2003) 'Twelve years on: outcomes and costs of deinstitutionalisation for people with mental health problems' *Mental Health Research Review*, Vol. 9, pp. 10-12.

Cava, H. and Kestenbaum, A. (1998) Work, rest and pay: a deal for personal assistance users.

Centre for Economic Performance's Mental Health Policy Group (2006) The depression report a new deal for depression and anxiety disorders.

Challis, D. et al. (2001) The value of multidisciplinary assessment of vulnerable older people: Personal Social Services Research Unit.

Charles, K.K. (2003) 'The Longitudinal Structure of Earnings Losses amongst Work-Limited Disabled Workers', *The Journal of Human Resources*, Vol. 38, No.3, pp. 618-646.

Clark, H and and Spafford, J. (2001) Piloting choice and control for older people: an evaluation, Joseph Rowntree Foundation.

Clark et al. (2004), Making direct payments work for older people: Joseph Rowntree Foundation.

Collignon, F. (1997) Is ADA successful? Indicators for tracking gains, USA.

Community Service Volunteers (2006) Making a difference through volunteering: the impact of volunteers who support and care for people at home.

Corden, A. et al. (2005) New Deal for Disabled People: An in depth study of Job Broker Service Delivery, National Centre for Social Research.

Croucher, K. (2006) Making the case for retirement villages, Joseph Rowntree Foundation.

Cuellar, A.E (2000) Consumer-Directed Home and Community Services Programs in Five Countries: Policy Issues for Older People and Government: USA.

DeLong, G. (1985), Economics and Independent Living, Research and Training Centre on Independent Living, University of Kansas.

Department of Health (2001), Valuing People: A New Strategy for Learning Disability in the 21st Century.

Department for Work and Pensions (2004) Independent Living in Later life.

Department for Work and Pensions (2004) Independent living in later life: literature review.

Department for Work and Pensions (2006) Making a difference: tackling poverty - a progress report.

Disability Research Institute (2005) Three reports to evaluate the vocational Rehabilitation programme, USA.

Doty P. et al. (1996) Consumer-directed models of personal care: Lessons from Medicaid, USA.

Duffy, S. (2004) In control (self-directed support).

Duffy, S. (2005) Individual budgets: transforming the allocation of resources for care.

Emerson, E. et al. (2005) Adults with learning difficulties in England 2003/04: National Statistics, NHS.

European Commission (2005) Disability mainstreaming in the European Employment Strategy, Belgium.

European Research Initiative (2005) Included in Society: Results and recommendations of the European Research Initiative on Community Based Residential Alternatives for Disabled People.

Evans, J. (2003), The Independent Living Movement in the UK, [www.independentliving.org/docs6/evans2003.html](http://www.independentliving.org/docs6/evans2003.html)

Frisch, J. (2000) Some notes on the economics of disability, Australia.

Frisch, J. (undated) The benefits of accessible buildings and transport: an economist's approach, Australia.

Frisch, J. (2001) Towards a disability allowance: offsetting the costs of disability: Faculty of Commerce and Economics, The University of New South Wales, Australia.

Fruin, D. (2000), New Directions for Independent Living, Inspection of Independent Living Arrangements for younger disabled people, Social Services Inspectorate, Department of Health

Gillinson, S. et al. (2005) Independent Living: The right to be equal citizens.

Glendinning, C. et al. (2000) Buying independence: using direct payments to integrate health and social services.

Glendinning, C. et al. (2006), *Minding the Money: Carers and the Management of Financial Assets in Later Life*, Report of a Scoping Study, Social Policy Research Unit, University of York.

Grammenos, S. (2003) *Illness, disability and social inclusion*.

Gravelle, H. et al. (2006) Cost-effectiveness of interventions to support self-care: A systematic review. *International Journal of Technology Assessment in Health Care*, Vol. 21, No. 4, pp. 423–432.

Greenwood, C. and Smith, J. (1999) *Sharing in ExtraCare*.

Harris, J. (2000) *Choice and Empowerment for People with a Learning Disability*: British Institute of Learning Disabilities.

Hendey, N. and Pascall, G. (2004) *Disability and transition to adulthood: the politics of parenting*.

Henwood, M and Hudson, B (2006) *Cash for care lifts off (Independent Living Fund)*.

Hester Adrian Research Centre, Manchester University (1996) *Residential provision for people with learning disabilities: a research review*.

Hoerger, T. et al. (1996) *Public subsidies, private provision of care and living arrangements of the elderly, USA*.

Howard, M. (2003), *Not just the job: report of a working group on disabled people using personal assistance and work incentives*: Joseph Rowntree Foundation.

Joseph Rowntree Foundation Task Group on Housing, Money and Care for Older People (2004) *From welfare to well-being - planning for an ageing society*.

Kestenbaum, A. (1996), *Independent Living: A Review*: Joseph Rowntree Foundation.

Kestenbaum, A. (1999) *What price independence? Independent living and people with high support needs*: The Policy Press.

Kestenbaum, A. (1999) *The Costs of Independent Living*: Joseph Rowntree Foundation.

Knapp et al. (2005), *Intellectual disability, challenging behaviour and*

cost in care accommodation: What are the links? *Health & Social Care in the Community*, Vol. 13, No. 4.

Könczei, G. (1999) *Rethinking disability and discrimination: A social and economic approach*: Budapest University of Economics (European Studies Center).

Local Government Association and the Association of Directors of Social Services (2003), *All Our Tomorrows: Inverting the triangle of care*.

Loumidis, J. et al. (2001) *Evaluation of the New Deal for Disabled People Personal Adviser Service pilot*, National Centre for Social Research.

Lundsgaard, J. (2005) *Consumer Direction and Choice in Long-Term Care for Older Persons, Including Payments for Informal Care: How Can it Help Improve Care Employment and Fiscal Sustainability? Outcomes*, OECD.

McNulty, A. (2005) *Making home care for older people more flexible and person-centred*.

Macfarlane, A. (2002) *A response to the Best Value review of direct payments in Wiltshire undertaken by disabled people*.

Machin, D. and McShane, D. (2001) *Providing free personal care for older people*: Scottish Executive Central Research Unit.

Mental Health Foundation (2004) *Childhood and Adolescent Mental Health: understanding the lifetime impacts*.

Miller et al. (2006), *Disabilist Britain: Barriers to Independent Living for Disabled People in 2006*, Demos.

Mind (2006), *With us in mind*, Service user recommendations for advocacy standards in England.

Morris, J. (2004) *Social Model Assessment Team Pilot Project: Report of Evaluation*.

Nadash, P. and Zarb, G. (1994) *Cashing in on independence: comparing the costs and benefits of cash and services*.

National Audit Office (2005), *Gaining and retaining a job: the Department for work and Pensions' support for disabled people*, Department for Work and Pensions.

Netten, A. et al. (2006), *Measuring Personal Social Services Outputs for*

National Accounts: Services for Older People, PSSRU Discussion Paper 2267/3, Personal Social Services Research Unit, University of Kent.

NHS (2006) Caring for people with long-term conditions: an education framework for community matrons and case managers.

OECD (2005) Breaking the Barrier. Thematic Review on Reforming Disability Policies to Improve Work Incentives - Agenda Item 4: Oral Statement by the Director, France.

Oldman, C. (2003) Deceiving, theorizing and self-justification: a critique of independent living, IN Critical Social Policy.

Olsen, R. (2004) Supporting Disabled Adults as Parents.

Palmer, G., Carr, J. and Kenway, P. (2005) Monitoring poverty and social exclusion 2005: Joseph Rowntree Foundation.

Physical Disability Council of New South Wales (1997) The Costs of Disability, Australia.

Poole, T. (2006) Direct Payments and Older People (Appendix for the Wanless Social Care Review): Kings Fund.

Prime Minister's Strategy Unit (2005) Improving the life chances of disabled people in the UK today.

Prince et al. (1995) 'Self-managed versus agency provided personal assistance care for individuals with high level tetraplegia', American Congress of Rehabilitation Medicine and American Academy of Physical Medicine and Rehabilitation.

Radia, K. (1996) Housing and mental health care needs of Asian people.

Ratzka, A.D. (2002) User control over services as a precondition for self-determination, Sweden.

Raynes et al. (2006), The Report of the Older People's Inquiry into 'That Bit of Help': Joseph Rowntree Foundation.

Reiff, H.B. and Shessel, I. (1999) 'Experience of Adults with Learning Disabilities: Positive and Negative Impacts and Outcomes', Learning Disability Quarterly, Vol. 22, No.4, pp. 305-316.

Rigg, J. (2005) Labour Market Disadvantage amongst Disabled People: A Longitudinal Perspective, CASE Paper 103: Centre for Analysis of Social Exclusion.

Robertson, J. et al. (2005) The Impact of Person Centred Planning: Institute for health research, Lancaster University.

Romeo, R. & Knapp, M. (2004?) The Economic Impact of Person Centred Planning.

Roulstone, A. and Barnes, C. eds. (2005) Working futures? Disabled people, policy and social inclusion: The Policy Press.

Ryan, T. (1998) The Cost of Opportunity: Purchasing strategies in the housing and support arrangements of people with learning difficulties: Values for Action.

Sainsbury Centre for Mental Health (2003) The economic and social cost of mental illness, Sainsbury Centre for Mental Health Policy Paper 3.

Sanderson, H. et al. (1997) People Plans and Possibilities: exploring a person centred planning.

Sanderson, H. et al. (2006) In Control: the story so far (support for disabled people).

Schneider et al. (2003), Formal and informal care for people with dementia: variations in costs over time, *Ageing & Society*, Vol. 23.

Scottish Executive (2003) Supporting People, supporting independent living.

Simons, K. (1998), Supported living and supported employment: opening up opportunities to people with learning difficulties: Joseph Rowntree Foundation.

Simons, K. (2001) The bottom line: incentives and disincentives for a wider range of housing and support options.

Smith et al. (2004) Disabled people's cost of living: Joseph Rowntree Foundation.

Social Exclusion Unit (2004) Mental Health and Social Exclusion.

Social Exclusion Unit (2006) A Sure Start to Later Life.

Task Group on Housing, Money and Care for Older People (2004) From welfare to well-being - planning for an ageing society: Joseph Rowntree Foundation.

Taylor, R. and Webb, J. (1997) In a state of independence (Independent Living Scheme).

Thornton, P. (2005) 'Disabled People, Employment and Social Justice', *Social Policy & Society*, Vol. 4, No.1, pp. 65-73.

Tibble, M. (2005) 'Review of existing research on extra costs of disability', DWP Research Paper, Working Paper No. 21.

Tilly et al. (2000), Consumer-Directed Home and Community Services Programs in Five Countries: Policy Issues for Older People and Government.

Ungerson, C. (1997) 'Give Them the Money: Is Cash a Route to Empowerment?', *Social Policy & Administration*, Vol. 31, No.1, pp. 45-53.

Ungerson, C. (1999) 'Personal assistants and Disabled People: An Examination of a Hybrid Form of Work and Care Work', *Employment & Society*, Vol.13, No. 4, pp. 583-600.

Values into Action, (1995) Increasing user control in social services: The value of the service brokerage model: Joseph Rowntree Foundation.

Wanless, D. (2006) Securing good care for older people: taking a long-term view: Kings Fund.

Wiener, J.M. (2000) State Cost Containment Initiatives for Long-Term Care Services for Older People, USA: The Urban Institute.

Wilson, L. (2004) Empowerment or tokenism? Service-user involvement within the local authority.

Zarb, G. (2001) Haringey on Call Support Service.

Zarb, G. (2003) "The Economics of Independent Living." Internet publication URL: [www.independentliving.org/docs6/zarb2003.html](http://www.independentliving.org/docs6/zarb2003.html). In the forthcoming English version of: Alonso, J. Vidal Garcia. 2003. "El Movimiento de Vida Independiente, Experiencias Internacionales." ("The Independent Living Movement: International Experiences").

Author not listed (2003) Evaluation of the Centers for Independent Living Program, USA.

