

The costs and benefits of independent living

Executive summary

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The concept of Independent Living

- 1.1 Independent Living (IL) 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.
- 1.2 Central to 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.
- 1.3 The concept of Independent Living is based upon a social, rather than a 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.

Aims and objectives of the study

- 1.4 The Office for Disability Issues (ODI) commissioned SQW Limited (SQW) to identify and review the costs and benefits of investment in Independent Living for disabled people. The review was required to examine the extent to which providing disabled people with more choice and control over the support they need is cost effective. 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. It will also feed into the ODI's 'invest to save' proposals to be made to HM Treasury ahead of the Comprehensive Spending Review (CSR) 2007.
- 1.5 The objectives of the study were twofold:
- An extensive review of the evidence and literature already available on the potential costs and benefits associated with IL support, as compared to more conventional forms of service provision.
 - A close examination of individual scenarios, through a series of case studies, 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 literature review

Methodology

- 1.6 The Terms of Reference for the Independent Living literature review stated that the aim was 'to cover evidence concerning the costs and benefits of giving disabled people more choice and control over the support they require'.
- 1.7 We adopted a clear methodology for conducting the literature review, establishing an analytical framework for the review, defining search terms, identifying sources for the literature search, developing a template for recording, analysing and synthesising findings.
- 1.8 The analytical framework incorporated an initial typology of costs and benefits associated with both conventional support and

IL, broken down into three levels - individual, service provision and the exchequer. A vast range of sources were interrogated including peer reviewed journals, UK and international government funded research, articles and papers published by research institutions. We identified close to 200 documents, which were narrowed down to 110, by using a set of quality criteria to rate the relevance of the documents to the study. This formed a 'core list' for the review.

Characteristics of the available evidence

- 1.9 The literature identified a range of support mechanisms that are designed to deliver the objectives of Independent Living such as personal assistance, consumer-directed care, home care, person centred planning, Direct Payments and Individual Budgets.
- 1.10 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 are faced with in their daily lives. Similarly, the evidence and advocacy of IL has increased significantly, with a wide range of literature discussing the rationale for mechanisms that deliver IL objectives and highlighting the potential benefits Independent Living support can offer to both disabled people and older people.
- 1.11 The available evaluation evidence tended to discuss the efficacy of specific IL programmes, comparing these with support delivered through institutional settings and traditional means. However, these discussions were rarely accompanied by a rigorous discussion of the costs and benefits of the two alternative approaches.
- 1.12 It emerged from the literature review that there was considerably more research and data on costs than on benefits. This is not entirely surprising given the notorious difficulties in valuing and measuring benefits, especially when they refer to improvements in the quality of life. Data on the costs of specific types of care, and cost variation by setting, were extensive, particular at the individual level. But there was very little discussion of opportunity costs.
- 1.13 Even where quantified and non-quantified costs and benefits

were available, the methodological implications require careful assessment. While studies discussing conventional support often deployed robust methods of measuring impact, there appears to be relatively little research that uses similar methods to evaluate the costs and benefits of IL.

- 1.14 The gaps in the availability of cost and benefit data were quite marked. From our extensive search and review it was clear that, as yet, there has been 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 IL 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 IL options for individuals, very few have managed to deploy robust methods to value benefits quantitatively. Cost data was more forthcoming at service delivery level, compared to individual and macro-economic level, but again evidence on benefits is sparse.
- 1.15 Partly responsible for the lack of robust cost and benefit data at individual, service delivery and macro-economic level, is the relative recency of the Independent Living agenda both in terms of research and implementation. Many Independent Living options are very new or still in pilot form. This precludes a longitudinal analysis, which would illustrate the long-term cost and benefit impacts.
- 1.16 The literature does make 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. However, there is an absence, at present, of robust figures to substantiate these projections. It is also too early to assess key qualitative outcomes such as inclusive social relationships and community engagement.
- 1.17 A further issue that the literature review exposed 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.

Conclusions from the literature review

- 1.18 Having made the above caveats, the available literature does enable us to draw some preliminary conclusions. Published material to date indicates that the delivery of Independent Living support to disabled people is more cost effective, or at least no more expensive, than traditional care provision.
- 1.19 There was particular evidence at service delivery 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 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 IL support.
- 1.20 Moreover, despite difficulties in valuation, there is also extensive qualitative evidence on Independent Living benefits and the considerable improvements 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.

Case studies and consultations

Methodology

1.21 In order to undertake some primary qualitative research into specific Independent Living support mechanisms five different scenarios, as shown in Table 1 below, were selected by the ODI Steering Group.

Table 1 Case study scenarios

- Out-of-authority residential placements for disabled young people
 - Disabled parents
 - Advocacy support to help job retention
 - Disabled people with high levels of support needs in institutional provision
 - Older people
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1.22 For each case study, the Steering Group provided SQW with a list of identified stakeholders, including 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 both individuals¹ 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.

1.23 It must be stressed that the case studies are illustrative rather than representative. We do not make any claim that any of the case studies are typical or representative. Instead the scenarios and information are provided to illustrate the potential contrasts in costs and benefits.

1.24 In order to extract the relevant information about the costs and benefits of both conventional support and Independent Living options, we constructed a core discussion guide to form the basis for the interviews; it was adapted slightly to correspond with the each type of consultee.

1.25 Each case study permitted an in-depth scrutiny of service recipients' experiences, identifying costs and benefits associated with IL and comparing these with conventional forms of care delivery.

¹ 1.26 We supplemented the case study qualitative research with some
The names of all individuals that we interviewed have been changed to protect their anonymity.

strategic consultations with professionals and policy experts to gain a view of the overall implications of investment in and implementation of the IL agenda at service and macro-economic level.

Conclusions from the case studies

- 1.27 The main messages that emerged from the case study investigations largely corroborated the literature review findings. As found in the published material, IL 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.
- 1.28 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 IL 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 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 individual level.

- 1.29 The case studies and strategic consultations, served to reinforce the already extensive evidence on qualitative benefits of IL 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.
- 1.30 This last point supports 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.

Conclusions about the service delivery and macro-economic implications

- 1.31 The additional information obtained through the strategic consultations on the costs and benefits at service delivery and macro level further 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 were the arguments about economies of scale and that existing service provision actually serves the needs of those individuals who do not want the responsibility of directing their own care and, instead, prefer the security of decisions being made for them.

- 1.32 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 was 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.
- 1.33 In terms of Independent Living support options, it was widely acknowledged that, particularly in the short term, IL implementation 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 augment these transition costs. Whilst these two issues may require 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. 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 it is the latter groups that are required to make the upfront investment.
- 1.34 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.

- 1.35 Interestingly consultation evidence suggests that, on a macro-economic level, IL 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, simultaneously, the benefits bill will also be reduced. Moreover, in the long term, the demands on other public services, particularly the health service, is expected to be considerably less.

Overall conclusions

- 1.36 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.
- 1.37 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.
- 1.38 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.

- 1.39 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

Barriers

- 1.40 The analysis of costs and benefits of IL mechanisms also identified several barriers to the implementation of independent living. Aside from the upfront investment costs, a number of interviewees highlighted 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. There is somewhat of a vested interest 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 the IL agenda.
- 1.41 Language and cultural issues will also need to be overcome if Independent Living is to be properly implemented. Information about Independent Living options needs to be presented in accessible and comprehensible formats to potential service recipients and their families. To be of optimum use to both the individual and society, more timely and widespread dissemination of information needs to be considered.

Data gaps

- 1.42 There are significant gaps in evidence evaluating the costs and benefits of IL, compared to conventional provision. 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 attempt to quantify some of the frequently mentioned qualitative benefits.

Future approach

- 1.43 The literature and qualitative research undertaken for this review uncovered several key messages, which are significant when considering investment Independent Living. It was indicated that IL will not 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. 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.
 - 1.44 As highlighted by the Strategy Unit's report² 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 may need to be refreshed to permit a wider appreciation of the macro benefits of delivering Independent Living and to highlight the economic case for investment in IL support mechanisms.
 - 1.45 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
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- ² PMSU (2005), Improving the life chances of disabled people.

them to embrace wholesale IL implementation.