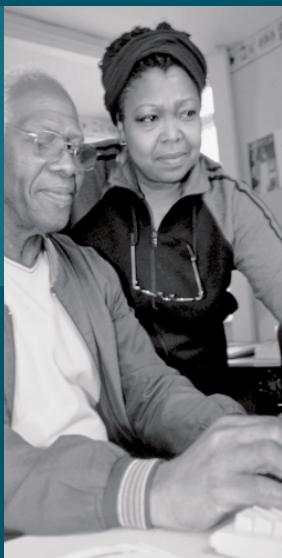


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- # Free Personal Care in Scotland



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FREE PERSONAL CARE IN SCOTLAND

Helen Dickinson and Jon Glasby

HSMC
Health Services Management Centre

King's Fund

This is one of a series of appendices to *Securing Good Care for Older People*. Download full report from www.kingsfund.org.uk/publications

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About HSMC

The Health Services Management Centre (HSMC) at the University of Birmingham is one of the leading centres for health services research, management education and development, postgraduate study and training in the United Kingdom. Established in 1972, its purpose is to promote better health by improving the quality and management of health care in the United Kingdom. This purpose is pursued through research, postgraduate education, training and consultancy. All HSMC staff are committed to combining intellectual rigour with practical relevance in their work and are involved both in developing new ideas and in applying them to real life health care problems and issues. HSMC staff come from a variety of backgrounds. A number have experience as senior managers and clinicians in the National Health Service (NHS) and health care systems in other countries. Others have pursued an academic career path and have held appointments in universities and related institutions. All are committed to working in the middle ground between practice and theory and demonstrating the value of ideas in action. HSMC's health and social care partnerships programme is one of the leading centres for research and development with regard to inter-agency working.

Acknowledgements and authors' note

HSMC is grateful to all those individuals and organisations who provided background information for this paper. The following document reflects our understanding of the data and opinion available at the time of writing (November 2005). However, we understand that a new study of free personal care in Scotland may become available from the Joseph Rowntree Foundation soon after publication of this paper, and the following discussion may need revisiting once these findings are made public.

Executive summary

The advent of free personal care for older people in care homes and at home was a defining moment in the development of UK political devolution. After all the controversy and debate surrounding the 1999 Royal Commission on Long Term Care, Scotland's decision to implement the Commission's main recommendations was a decisive break from Whitehall's approach and seemed to offer a key opportunity to learn from the implications of this policy for an English context. However, this soon proved to be far from straightforward, with a series of ongoing debates about:

- diagnostic equity and the best use of scarce public resources
- the extent to which free personal care might benefit the 'middle classes' rather than those on low incomes
- the extent of initial understanding of the nuances behind a seemingly simple, but potentially very complex and subtle policy change.

In particular, learning lessons from Scotland is made more complex by a range of key issues, including:

- a lack of initial monitoring and evaluation (which has been heavily criticised by Audit Scotland)
- the need to make assumptions about future changes in demand, population, family care and unmet need
- the potential for local variations in implementation.

Since the introduction of free personal care in Scotland in July 2002, the number of people receiving free personal care in a care home and the number of people receiving free nursing care have both risen by 15 per cent, while the number receiving free personal care at home has risen by 74 per cent. However, trends in domiciliary care suggest that more intensive support may be being provided for fewer people (and hence that the policy of free personal care may not have led to a large number of new service users).

Although free personal care has been widely billed as being a good natural experiment, it has been in place for only a short period of time and it is too early to say whether or not it has been successful. From the beginning, this may have been more of a political and an ethical issue than an economic one, and evaluating the impact of the policy will be difficult given this context and a potential lack of robust financial data. Despite this, the fact that the policy seems to have been welcomed by some sections of the general public and has been implemented across Scotland in a relatively short space of time suggests that the notion of free personal care may be feasible in the short term (if there is sufficient political will) and offers an opportunity to learn lessons from this policy for other national contexts. However, major concerns about the financial sustainability of the policy remain, and the lack of monitoring and evaluation to date has been strongly criticised.

Background and introduction

While still in opposition, New Labour pledged its commitment to supporting older people and to improving health and social care services. As part of its 1997 manifesto, the party promised to establish a Royal Commission to explore the funding of long-term care. For some time, this had been an area of increasing political and policy significance, with longstanding concerns amongst older people and campaigning groups about the costs of long-term care and their impact on older people and their families (see Glasby and Littlechild 2004 for an overview of these debates and for a summary of the policy context).

After Labour's election victory in May 1997, this promise was duly delivered, with the creation of the Royal Commission on Long Term Care, chaired by Professor Sir Stewart Sutherland, Principal and Vice Chancellor of the University of Edinburgh. Established in December 1997, the Commission was tasked with examining the short- and long-term options for a sustainable system of funding of long-term care for older people, both in their homes and in other settings, and to recommend how, and in what circumstances, the cost of such care should be apportioned between public funds and individuals. When the Commission presented its recommendations in March 1999, its analysis was based in part on a strongly-worded but very accurate critique of the current funding system:

The current system is particularly characterised by complexity and unfairness in the way it operates. It has grown up piecemeal and apparently haphazardly over the years. It contains a number of providers and funders of care, each of whom has different management or financial interests which may work against the interests of the individual client. Time and time again the letters and representations we have received from the public have expressed bewilderment with the system – how it works, what individuals should expect from it and how they can get anything worthwhile out of it. We have heard countless stories of people feeling trapped and overwhelmed by the system, and being passed from one budget to another, the consequences sometimes being catastrophic for the individuals concerned.

(Royal Commission on Long Term Care 1999, p 33).

A key issue was the way in which the distinction between health (which is typically free at the point of delivery) and social care (which is means-tested) discriminates against people who have personal care needs that do not fall under the jurisdiction of the NHS. To illustrate this point further, the Commission quoted the example of a person with Alzheimer's disease forced to pay for care that would be free to someone with cancer:

Whereas the state through the NHS pays for all the care needs of sufferers from, for example cancer and heart disease, people who suffer from Alzheimer's disease may get little or no help with the cost of comparable care needs. All these conditions are debilitating, but Alzheimer's disease cannot yet be cured by medical intervention. However, a mixture of all types of care, including personal care will be needed. This is

directly analogous to the kind of care provided for cancer sufferers. The latter get their care free. The former have to pay.

(Royal Commission on Long Term Care 1999, p 65).

In place of the traditional divisions between health and social care, the Commission proposed a radical restructuring of the current system which would distinguish between three different types of costs:

- **living costs** (food, clothing, heating amenities and so on)
- **housing costs** (the equivalent of rent, mortgage payments and council tax)
- **personal care costs** (the additional cost of being looked after arising from frailty or disability).

Whereas service users would continue to pay their own housing and living costs, personal care would be free after an assessment of need and paid for by general taxation.¹ These distinctions would also be applied to services for younger people and to community-based services such as domiciliary care and aids and adaptations, with personal care services once again exempt from charges.

While the notion of free personal care has attracted the most attention, the remainder of the Commission's report contained a number of additional proposals, ranging from rehabilitation to promoting cultural sensitivity, and from direct payments to changes in social security regulations. However, although the government accepted most of these recommendations, it rejected the central plank of the Commission's report: the call for free personal care. Although making personal care free would cost a substantial sum of money, the government argued, it would merely shift the cost of such services from the individual to the state, without necessarily improving those services or leading to any increases in the overall amount of money invested in such provision at all. Instead, the government pledged to introduce free NHS nursing care, so that the costs of 'registered nurse time spent on providing, delegating or supervising care' would be free to everyone who needs it, whether they live at home, in residential care or in a nursing home (Department of Health 2000, p 11) from October 2001. This meant that older people in residential or nursing care would continue to pay for their personal care and accommodation costs as before:

There can be no justification for charging people in care homes for their nursing costs. We will make nursing care available free under the NHS to everyone in a care home who needs it... This change will benefit around 35,000 people at any time. They could save up to around £5,000 for a year's stay in a nursing home. The introduction of free nursing care in every setting will provide the right incentives to the NHS and social services to work together to provide the modern quality care that people need. It will encourage the NHS to provide rehabilitation services that people are able to benefit from. It will reduce the perverse incentive to discharge people too early to social services funded care. It will create a fairer system, where people can receive the nursing care they need wherever they live, paid for or provided by the NHS. It will end the most obvious inconsistency in the funding of long term care.

(Department of Health 2000, pp 11–12).

As a result, all nursing care in care homes is now provided free of charge, with service users assessed according to the Registered Nursing Care Contribution (RNCC) and receiving funding for low, medium or high needs.

From the beginning, the Commission's findings and the government's response have been highly controversial. Shortly after the publication of the 1999 report, there was considerable media speculation that the government would reject elements of the Commission's proposals, and the Commission chair was quoted as being concerned about official 'procrastination' and attempts to dilute the report (see, for example, Community Care 2000a). Some four years after the original report, moreover, a statement by nine members of the Commission (2003) accused the government of 'betraying' older people and emphasised the 'the huge ethical, conceptual and practical difficulties in distinguishing between the 'nursing' and 'personal' care of ill and disabled people' (para.17) – a distinction which still seems to many to be unfair, unhelpful and unworkable. Above all, the Commission was critical of the way in which this policy effectively makes nurses the gatekeepers to free care, and is a service- rather than a needs-led response (para.20):

There is more than a hint that government has decided how much money should be spent on care funding and has devised a pragmatic way of spending it without regard to patients' needs. This is the opposite of how older people should be looked after.

Following political devolution, moreover, different countries of the United Kingdom have adopted different approaches to the Commission's recommendations, with Scotland in particular developing a markedly different approach to Whitehall. Wales have recently ruled out backing a free personal care policy unless it is funded by extra taxation (Hayes 2005) and, while free nursing care was introduced in Northern Ireland, personal care is still charged for. Against this background, the remainder of this discussion paper describes the key features of the Scottish system, emerging lessons and key implications for future policy and practice.

Free personal care policy in Scotland: a brief history

During debates about free personal care in Scotland, different commentators have highlighted a complex series of issues, including:

- diagnostic equity and the best use of scarce public resources
- the extent to which free personal care might benefit the 'middle classes' rather than those on low incomes
- the importance of the opportunity for policy divergence in an era of devolution
- the extent of initial understanding of the nuances behind a seemingly simple, but potentially very complex and subtle, policy change.

Initially, the Scottish Executive responded to the Sutherland report in October 2000 (Scottish Executive 2000) by rejecting the recommendation to fund personal care from general taxation. This was based on the grounds that the funds would be better spent on investing in improved standards of care and ensuring fair access to services for a larger number of older people. There was broad agreement with Westminster that, although the principle of free personal care was a good one, in practice it would be too costly and potentially counterproductive. Under the First Ministership of Donald Dewar, Susan Deacon (the Minister for Health and Community Care) instead announced a £100 million investment in community services for older people over three years (Community Care 2000). From the beginning, however, this was a controversial issue, and there was support for free personal care from the Liberal Democrats, the SNP and some Labour backbenchers. Given strong Liberal Democrat support in particular, free personal care was an important topic so early in the life of devolution, and there was a risk that the Liberal Democrats would withdraw from the Scottish LibLab coalition over the issue.

Meanwhile, the Scottish Parliament's Health and Community Care Committee had begun an inquiry into care in the community in October 1999, seeking to explore issues arising from the Sutherland report, resource transfer issues, the co-ordination of services, best practice and views on the best means of delivering the most appropriate care to patients. The Committee published its report in November 2000 (Scottish Parliament 2000), with a recommendation that personal care should be provided free on the basis of assessed need.

Following the sudden death of Donald Dewar in October 2000, Henry McLeish became the First Minister of the Scottish Executive and the issue of free personal care became a 'political hot potato' (McKay 2001). There had continued to be support for the policy within both the Scottish Parliament and the general public, and in January 2001 there was a parliamentary debate on a Liberal Democrat party motion for the implementation of Sutherland's free personal care recommendation. The motion was backed by McLeish, in what seemed by some at the time as a political u-turn in order to avoid an Executive defeat and damage to the coalition (Scott and Carvel 2001). Subsequently, the Scottish Executive

announced its intention to move towards implementing the policy for the over-65s, and a Care Development Group (CDG) was established to bring forward the proposal. Chaired by the Deputy Minister for Health and Community Care, the group was tasked with deliberating on these issues and to report to the Scottish Executive in very tight timescales (around six months). When the CDG subsequently published its recommendations in September 2001 (Care Development Group 2001), it endorsed the principle of free personal care for older people in care homes and for community services.

From the beginning, the notion of free personal care policy was promoted as being one driven by issues of equity. As the CDG states:

Free personal care is right in principle because it will remove the current discrimination against older people who have chronic or degenerative illnesses and need personal care. It will bring their care in line with medical and nursing care in the NHS where the principle of free care based on need is almost universally applied and accepted.
(CDG 2001, p 10).

However, the introduction of this policy has raised a series of additional debates about equity. Westminster originally pressed McLeish not to introduce the policy as it would create the ultimate 'postcode lottery', with services based on where older people live (that is, in England or in Scotland) rather than on need (Scott and Carvel 2001). In contrast, others argue that this is entirely appropriate in an era of devolution (even if it may have been harder for some to accept such policy difference in the early stages of devolution). Some initial fears were also expressed that Scotland would experience mass migration of over-65s from other parts of the UK, but these have not been recognised thus far and may well rest on a misunderstanding of the full nature and likely impact of the policy. In addition, free personal care has been applied only to older people, not to younger people with physical impairments as recommended by Sutherland.

Perhaps the most important equity issue of all, however, relates to initial government opposition to free personal care following the Sutherland report: that this policy would significantly increase public expenditure on care homes, but without achieving additional investment above and beyond what individuals were already contributing to the cost of their care. Thus, on one level, free personal care is more about changing who pays, than the total amount of resource invested in services for older people.

In Scotland, the CDG estimated that at the time of reporting about 85 per cent of expenditure on older people's services came from the public purse. There were a considerable number of people living in residential and nursing homes who already had their fees paid in full or in part from public funds who were not affected by the free personal care policy as they already received their care as part of a package from the local authority. Those who paid for care at home would likely be receiving a mixture of domestic and personal care, and in reality most local authorities capped prices, so older people were paying much less than the true amount of the cost for their care. This has led to claims that the free personal care policy is one which in reality only benefits the middle classes (Bauld 2001). In contrast, others may well disagree – current earnings thresholds for people in a care home are around £19,500 per annum, so that anyone with property and savings worth more than this would pay for their own care (in a care home). In an era of greater home ownership and of the 'right to buy', having assets of £19,500 does not necessarily make an older person middle class.

As part of their deliberations, the CDG commissioned a range of research studies and carried out a wide consultation, placing advertisements in the press inviting the public to submit their views, hiring consultants to conduct a telephone survey of householders, running focus groups and conducting meetings with the public across Scotland. However, the results of the consultation posed some problems for the CDG; only 34 per cent of those surveyed by telephone thought free personal care should be provided to everyone, with a clear majority of 42 per cent supporting means testing (NFO System Three Social Research/MORI Scotland 2002). While this is not inconsistent with other surveys of how care should be funded, some commentators have suggested that these results may be explained in part by the complexity of free personal care (which involves detailed changes to current social security and community care arrangements). Given that free personal care was also being developed at the time of changes in Housing Benefit and the advent of Supporting People, the funding of services for older people was a difficult issue to understand at the time of the advent of free personal care, and it is not clear to what extent all key stakeholders understood the full nuances of the policy (personal communication).

The CDG report proved to be the basis for the Community Care and Health (Scotland) Act (Scottish Executive 2002b) which provides the legislative backing for implementing free care. The Act was implemented in July 2002 on a very tight timescale and in a politically charged atmosphere. An additional issue was also the rapid succession of First Ministers, with three different people occupying this post in a short space of time at crucial stages in the development of this policy. Perhaps as a result of this, the implementation of free personal care has not always been straightforward, and subsequent issues debated in the paper below may well relate to the pace and manner in which change was introduced.

Free personal care arrangements

The Community Care and Health (Scotland) Act 2002 requires that personal and nursing care shall no longer be charged for and sets out specific types of care that are not to be charged for, based wholly on the recommendations of the CDG. The Act also enables Ministers to set out in regulations detailed provisions concerning the delivery of free care, including making clear who will be eligible. The Act defines personal care as consisting of the following matters:

- **personal hygiene:** shaving, cleaning teeth, providing assistance cleaning mouth, keeping finger nails and toe nails trimmed, assistance with toileting, catheter/stoma care, incontinence laundry, skin care
- **food and diet:** assistance with food preparation, assisting fulfilment of special dietary needs
- **problems of immobility**
- **medical treatments:** applying creams or lotions, administering eye drops, applying dressings, oxygen therapy
- **general well-being:** dressing, assistance with surgical appliances, prosthesis, mechanical and manual equipment, assistance to get up and go to bed, provision of memory and safety devices, behaviour management and psychological support.

Despite detailed guidance (see, for example, Scottish Executive 2002a), any policy that seeks to define ‘personal care’ is bound to run into considerable definitional complexity, and there have been a number of debates about the precise meaning and application of the Act. This is hardly surprising, but may well be crucial, as the costings on which the policy was based may differ considerably depending on exactly which services are included within its remit.

More recently, the issue of definition has continued to be a key debate owing to the individual ways in which free personal care has been interpreted within different local authorities. Age Concern (2003) point out that fire-lighting services are a ‘grey area’; these services tend not to be covered but what happens in cases where the only way to heat water for bathing and so on is by lighting the fire? It could be quite feasible that, just as the differences between nursing care and personal care are not always apparent to service users (Waddington and Henwood 2005), neither are the differences between personal care and domiciliary care, particularly where there are local interpretations of the policy.

The actual implementation of the free care policy was put into two broad categories (Scottish Executive 2003): care in care homes and care at home. Guidance was provided on the procedures to be followed in both categories (as well as with respect to those already receiving personal care and those making applications after implementation).

Care in care homes

From 2002, care home residents aged 65 and over and meeting their own care costs (self-funders) received a flat-rate payment for personal care (£145). Those receiving nursing care (both under- and over-65) were to receive an additional £65 per week. Transitional arrangements applied to those already in care homes on 31 March 2002, and these individuals required no assessment of need to be eligible for payments. Those self-funders entering a care home after 31 March 2002 required an assessment of need to become eligible for personal or nursing care payments.

Crucially, self-funders continue to pay the remainder of their own costs, often described as living or accommodation costs (but are no longer eligible for Attendance Allowance; see below). As a result, it is a mistake to think that the free personal care policy means that social care is free in Scotland. The cost of an average care home is £420 per week, and self-funders represent about 40 per cent of Scottish care home residents. Therefore, if the state provides £210 per week (for free personal and nursing care), self-funders are still paying half at £210 per week. It is also worth comparing this figure with self-funders in care homes in England, where somebody in the highest of the three free nursing bands who is also receiving Attendance Allowance will be receiving £180 per week from the state (for free nursing care and in social security payments), in comparison with £210 in Scotland (Bell 2005). Viewed from this angle, it would appear that the Scottish system is not significantly more generous for everyone, and that the notion of free personal care is more nuanced than has often been portrayed. What is significant, however, is the source of the funding – in England, the cost of the care home place would be partly funded by Attendance Allowance and hence by a different budget and government department.

Care at home

From July 2002, people aged 65 and over received personal care at home free of charge. All eligibility for free personal care is subject to an assessment of need by the local authority, but eligibility is made irrespective of income, capital assets, marital status or the care contribution made by an unpaid carer. Non-personal care services will continue to be subject to charges at the discretion of the local authority. Receipt of Attendance Allowance and Disability Living Allowance is not affected by receiving free personal care at home. Interestingly, it is much harder to find data on the financial implications of free personal care at home than it is for care home fees, and much of the debate to date has focused on institutional rather than community-based costs.

Calculations of rates, demand and future projections

Funding issues

The Sutherland report suggested that personal care costs in a residential home would be about £122 per week and nursing costs £217 at 1995 prices, with an additional living and housing component of £120 per week (Royal Commission on Long Term Care 1999, para. 6.40). Subsequently, the Scottish Executive Health Department (SEHD) estimated that, in the light of the Sutherland estimates, year one of the policy would cost £125 million (Audit Scotland 2005). The CDG estimated £285 per week as the combined living and personal care in year one, but given the Sutherland costings, this seems quite low. The CDG recommended that a payment of £90 per week should be made for personal care, and a further payment of £65 per week should be made where individuals qualify for nursing care (Care Development Group 2001). However, this projection was made under the assumption that individuals would still be eligible for Attendance Allowance. The Department for Work and Pensions decided that Scottish care home residents in receipt of personal care money would lose eligibility for weekly Attendance Allowance payments of £55. Instead, the Scottish Executive has provided an additional £23 million to compensate for the loss of Attendance Allowance, with the weekly personal care rate increasing from £90 to £145 to make up for the deficit.

In their report the CDG highlighted the gap of £63 million which existed in 2001 between the grant aided expenditure (GAE) and budgeted expenditure across local authorities (p 29). There is a general feeling among some parties that community care is under-funded, which would clearly be compounded if the rates for personal and nursing care are set too low. The report from the Health and Community Care Committee inquiry stated that:

The Committee formed the view that fundamental problems exist in the funding of community care in Scotland. The committee is convinced that real spending on community care is currently set at an inappropriately low level, presenting an insurmountable barrier in realising service ambitions.

(Scottish Parliament 2000, p 4).

Against this background, community care services in Scotland have experienced similar debates to those in England about the extent to which care home places are adequately funded and about the potential impact on delayed transfers of care should homes need to close. There has also been a fear that care homes may respond to free personal care by raising their fees, as some anecdotal evidence alleges has happened in England accompanying the introduction of free nursing care. This could potentially create quite a paradoxical situation, where those self-funders who are predicted to benefit from the policy may find themselves with increased care home fees (although there is currently little evidence that this will be a major long-term issue).

The CDG also highlighted the lack of monitoring arrangements for money spent by local authorities on older people's services, while the Health and Community Care Committee identified a similar lack of financial clarity with regard to community care services (Scottish Parliament 2000). This made it difficult for the CDG to calculate either current amounts of money that were being spent on personal care, or to make future predictions about need, demand and costs. In particular, it is important to note that community care services were widely perceived to be experiencing a number of difficulties and debates at the time of the implementation of free personal care, and it is difficult to be clear about what was being spent on older people's services (and the value for money being achieved) before, during and after implementation.

Unmet need and informal care

However, the lack of clear data was not the only difficulty encountered in calculating projected expenditure, with figures for unmet need, population projections and levels of informal care also needing to be estimated. Unmet need was calculated from disability surveys and census data, where an analysis of aggregate data seemed to suggest a trend of modest continuing decline in disability among the population in private households (see Stearns and Butterworth 2001 for details). Furthermore the survey distinguishes between eleven day-time tasks and nine night-time tasks, and assesses what percentage of the older disabled population need assistance with these tasks. Unmet need was predicted to be less than ten per cent for older disabled populations in private households, with affordability reported as the reason for unmet need by only about nine per cent of people. Other reasons for unmet need, such as not knowing help was available, not knowing how to access help, or wanting to be independent, were reported more frequently.

In response, the CDG made a significant allowance for unmet need (more generous than their own calculations suggested was necessary), equivalent to about £50 million in year three of the policy's implementation. Nevertheless, critics have suggested there are a number of factors which have not properly been taken into account (see below for further discussion) and suggest that unmet demand may be at least twice this amount (Cuthbert and Cuthbert 2002). Should the level of unmet need prove to be much higher than predicted, then it would undoubtedly have a big effect on the numbers requesting free personal care.

As an indication of the potential numbers of those who may claim free personal care, the February 2005 figures for Scottish claimants of Attendance Allowance are 139,300 (Department for Work and Pensions 2005b), and approximately 57,000 claiming Disability Living Allowance (after those receiving mobility-only payments are excluded) (Department for Work and Pensions 2005a). All these claimants have passed some type of formal assessment based on their formal care needs, and might therefore reasonably think that they should be eligible for the personal care package (Cuthbert and Cuthbert 2002). In addition, initial costings and projections were based on the data available at the time of the CDG's deliberations in 2001, which creates two key problems. First, the latest population projections from the Government Actuary's Department show higher growth than their previous projections in the numbers of older people. The numbers of people aged 65 and over in the UK are expected to rise by 81 per cent over the next five decades: from 9.3 million in 2000 to 16.8 million in 2051. The numbers of people aged 85 and over are projected to grow even faster: from 1.1 million in 2000 to 4 million in 2051, an increase

of 255 per cent. Much of the need for long-term care in the older population comes from the latter group (Wittenberg *et al.* 2004; see the Wanless Review website for further demographic information).

Second, Stearns and Butterworth (2001) were commissioned to explore the anticipated demand for personal care by disabled older people in private households and the likely substitution effects arising from the introduction of free personal care. Their estimates of the numbers of disabled people in Scotland were derived from the Department for Work and Pensions' disability follow-up study to the Family Resources Survey of 1996/7 and the 1985 OPCS survey on disability. Stearns and Butterworth estimated that the older disabled population in private households in Scotland stood at 142,000. However, Cuthbert and Cuthbert (2005, p 36) suggest that there are a number of mistaken assumptions and technical difficulties with this estimate, and that the true figure may actually be 350,000. Stearns and Butterworth looked at the numbers of disabled people in private households and assumed that this is distinct from the population in special needs housing. Cuthbert and Cuthbert suggest this is a mistaken assumption, and that most special needs housing is categorised as private households by government departments. Furthermore, Cuthbert and Cuthbert also claim that Stearns and Butterworth's predictions of future demand are based on an incorrect assumption that the levels of disability in Scotland will decline in the future, when in actual fact, on the basis of Department for Work and Pensions' published figures, the disabled population actually increased significantly between 1988 to 1996 (from 3.4 million to 4.2 million) across Great Britain. However, there is no real consensus surrounding these figures, and so as yet it remains unclear how future population projections will impact on costings.

One of the biggest issues to factor into the calculation of the demand for free personal care is the amount of informal care provided in Scotland. The CDG worked on figures derived from a research project where the number of care hours were costed as if they were being supplied by care workers in the formal labour market, up to a maximum of 28 hours per week per person (after which individuals would hit an upper limit at which people would be likely to go into a care home). This estimated the annual replacement cost of informal care in Scotland at about £200 million (Leontaridi and Bell 2001). Potentially though, should the 7.5 per cent of the adult Scottish population who are estimated to be carers cease providing informal care, then this would increase the numbers wishing to claim free personal care far past those which were originally anticipated.

There is very little information on the substitution of care, but what is available from the United States suggests that substantial substitution away from informal care, as a result of the extension of formal provision of care services, is unlikely. It is thus broadly assumed in the CDG figures that levels of informal caring will remain constant over time. However, given the changing family structure that has been widely noted in recent policy documents (Department of Health 2005) along with the Executive's wish to keep as many people in their homes as possible (Scottish Executive News 2005), this may not be an accurate prediction.

Culture also plays a key role in both the factors of unmet need and informal care. Should there be a culture shift with individuals being more prepared to receive help from the state than to be independent, then this would increase the numbers requesting free personal care. A similar change could be experienced should there be a culture shift away from the provision of informal care.

Lack of monitoring and evaluation

In addition, Audit Scotland has recently published a scathing review of the way in which the predicted expenditure for the free personal care policy was derived (Audit Scotland 2005). In their view, the political imperative for a speedy introduction of free personal care, coupled with a lack of robust information, is likely to have undermined the ability of the Scottish Executive Health Department (SEHD) to cost the policy accurately. The Executive originally predicted that the free personal care policy would cost £125 million in year one, and were supported by the CDG (who costed the policy at £125 million per year in 2002–2004, rising to £137 million in 2007, £161 million in 2012, £189 million in 2017, and £227 million in 2022). The Committee noted that ‘the co-incidence’ in these costings by SEHD and the CDG (that is, both costing the policy at £125 million per year), emphasising that ‘allocations must be made on the basis of a realistic and accurate assessment of need – estimated costs must not be calculated to fit allocations.’ With costs already outstripping predictions nine months into the policy (£126 million instead of an estimated £107 million), the Committee was concerned that future predictions might also be inaccurate. In contrast, SEHD emphasised that this apparent over-spend may be the result of a lack of data about what local authorities were spending on personal care prior to the policy. The Committee also noted considerable inconsistency in the way local authorities provided data, and set out the following concerns.

- Given limited data, SEHD could not know with any certainty how much was being spent on personal care and could not cost the policy.
- Lack of information prevents comparing like with like before and after the implementation of the policy.
- SEHD had failed to monitor and evaluate the impact of free personal care, and had not undertaken a systematic risk assessment of the consequences of inaccurate estimates.

As a result, the Committee was clear that SEHD should review the cost of free personal care, ensure that projections are based on accurate information, match financial allocations to councils with needs, and evaluate the impact of the policy (and that monitoring and evaluation should have been put in place from the start, not three years in to the policy).

In contrast, others viewing the advent of free personal care would undoubtedly point out that much of the work done on the policy may have been based on the best possible data *under the circumstances*. Predicting future demand is not an exact science at the best of times, and this particular policy was made more complex by very tight timescales, the need to make assumptions about key future trends, and potentially inaccurate population data. Local authorities also have a range of different funding sources to monitor (including mainstream budgets, Supporting People, free personal care and funds to tackle delayed hospital discharges), all of which place additional strain on an arguably already overstretched IT system. Against this background, it is perhaps surprising that early expenditure did not outstrip predictions by more than has so far occurred.

Whilst participating in the Audit Scotland review, SEHD committed to assess the impact of free personal care and evaluate future costs. More recently, such research has been commissioned, and a Scottish Parliament Health Committee inquiry has been launched (due to report in summer 2006). A Joseph Rowntree Foundation study is also due to be published in January 2006.

Local authority interpretation

Although the Scottish Executive has laid down the legislative basis for free personal care and has provided guidance for local authorities, the interpretation and implementation is still very much down to individual authorities in practice. This has had a number of implications for the execution of the policy. While the following analysis relates to free personal care in Scotland, the underlying issues about understanding the gaps that can occur between central policy and local implementation are much more generic.

Although the Executive has stressed the importance of providing clear information on eligibility criteria and levels of quality of service provision, there have been criticisms that each local authority has interpreted the guidance differently, making monitoring and evaluation of provision difficult (Age Concern 2003). This lack of coherence may hinder long-term- planning and the provision of a single coherent policy covering Scotland. However, it may also be argued that the individual interpretation of the policy may make it more locally appropriate than if it were simply enforced on a top-down basis.

As part of the process of application for receipt of free personal care, the Executive very much puts onus on the action of the individual:

It is the individual's responsibility to approach the local authority if they want to seek public sector support for their care costs. If they are resident in a care home and in receipt of Attendance Allowance or Disability Allowance (care compact), they must notify the Department of Work and Pensions accordingly so these can be stopped in accordance with the rule.

(Scottish Executive 2003, p 26)

Despite an extensive information campaign run by the Executive publicising the introduction of free personal and nursing care, there has been some local variation between authorities as to the quality of information made available. An Age Concern telephone survey (2003) suggested that more than 20 per cent of older people were unfamiliar with the policy, and this would clearly impact upon the numbers of people who may apply for free personal care. If the findings of Stearns and Butterworth (2001) – that is, that a large proportion of unmet need is due to a lack of knowledge about the accessibility or availability of free personal care – are considered within this context, local authorities which provide better information and make their systems more accessible may find themselves with many more requests for free personal care than those which do not.

Similarly, the delivery of care is based on local protocols. Before an individual may receive payment towards personal care the guidance is very clear that they must undergo an assessment. Since April 2004, all of community care has been covered by the 'single shared assessment' process (Scottish Executive 2004d) meaning that older people do not have to undergo multiple assessments for community care. However, there has been some

criticism that some areas have considerable waiting times for assessment, and this may be used as a way of rationing the provision of free personal care, particularly for those at home (Age Concern 2003). In particular, payments for personal care may not begin until assessment has taken place, and there is no provision for the backdating of payments. The Joint Free Personal and Nursing Group has involvement from the Convention of Scottish Local Authorities (COSLA), the Scottish Executive, Scottish Branch of the Society of Local Authority Chief Executives and Senior Managers (SOLACE) and the Association of Directors of Social Work (ADSW). On the matter of waiting lists, the Joint Group has stated that free personal and nursing care is a well-funded policy, and would not expect waiting lists to arise as a result of a lack of funding (Scottish Executive 2004b).

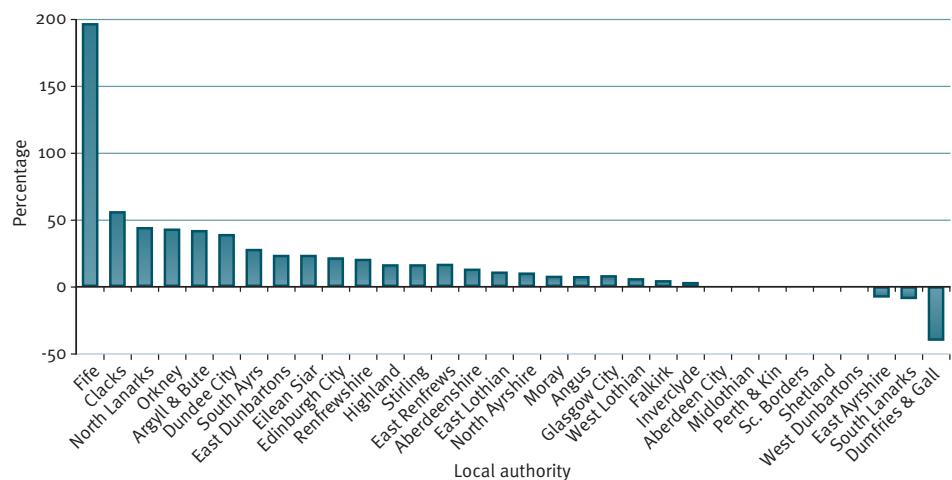
Summary of expenditure and activity

According to Scottish Executive statistics (Scottish Executive 2004e), the number of people receiving free personal care in a care home has increased steadily, with a 15 per cent rise over the two-year period of 1 July 2002 to 30 June 2004. This trend is demonstrated by local authority in Figure 1, which shows that the majority of local authorities showed an increase in free personal care clients (with only three experiencing a decrease in numbers).

The number of people receiving free personal care at home has increased steadily by 74 per cent over the same period, as demonstrated in Figures 2 and 3. The former chart again shows that most local authorities saw an increase in free personal care clients, with only one having fewer people in receipt of free personal care at home in 2004.

Figure 3 displays the total numbers of people receiving free personal care and nursing care by location of provision. The number of people in receipt of free nursing care has risen at the same rate as those in receipt of free personal care in care homes over the two-year period (15 per cent). While the number of people receiving free personal care at home rises much more steeply, this might to some extent be expected given that existing care home residents received free personal care immediately, whereas those in their own homes must undergo an assessment. In addition, home care data suggests that the number of home care recipients has fallen over time, rising again by under two per cent in 2004/5. At the same time, the number of hours of home care provided has increased rapidly (see Figure

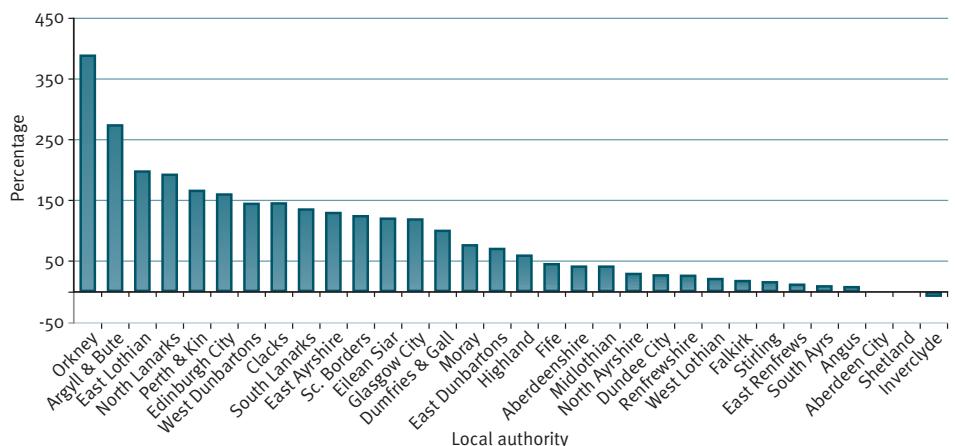
1 PERCENTAGE CHANGE IN NUMBER OF PEOPLE RECEIVING FREE PERSONAL CARE IN A CARE HOME, BY LOCAL AUTHORITY, 1 JULY 2002 TO 30 JUNE 2004



Source: Scottish Executive, 2004e

2

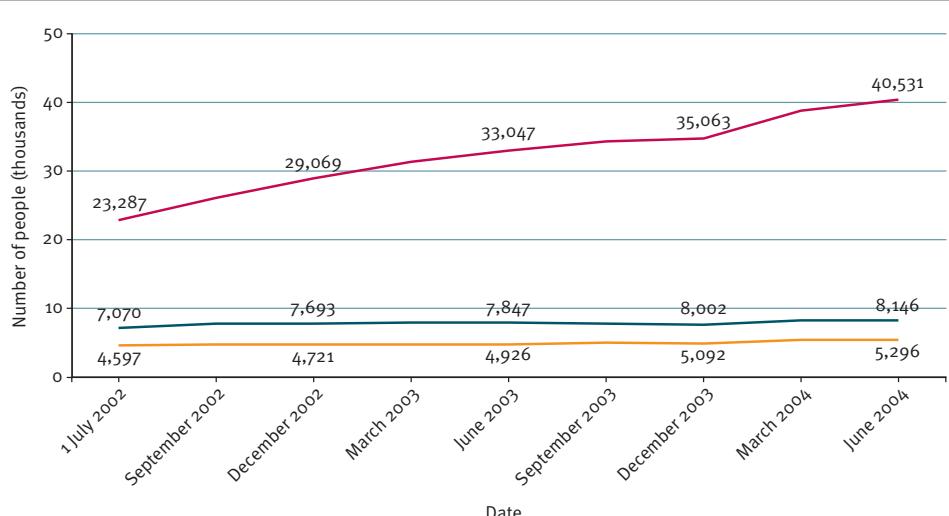
PERCENTAGE CHANGE IN NUMBER OF PEOPLE RECEIVING FREE PERSONAL CARE AT HOME, BY LOCAL AUTHORITY, 1 JULY 2002 TO 30 JUNE 2004



Source: Scottish Executive, 2004e

3

NUMBER OF PEOPLE RECEIVING FREE PERSONAL CARE AND NURSING CARE, BY LOCATION OF PROVISION, 1 JULY 2002 TO 30 JUNE 2004



KEY

- Free personal care at home
- Free personal care in a care home
- Free nursing care in a care home

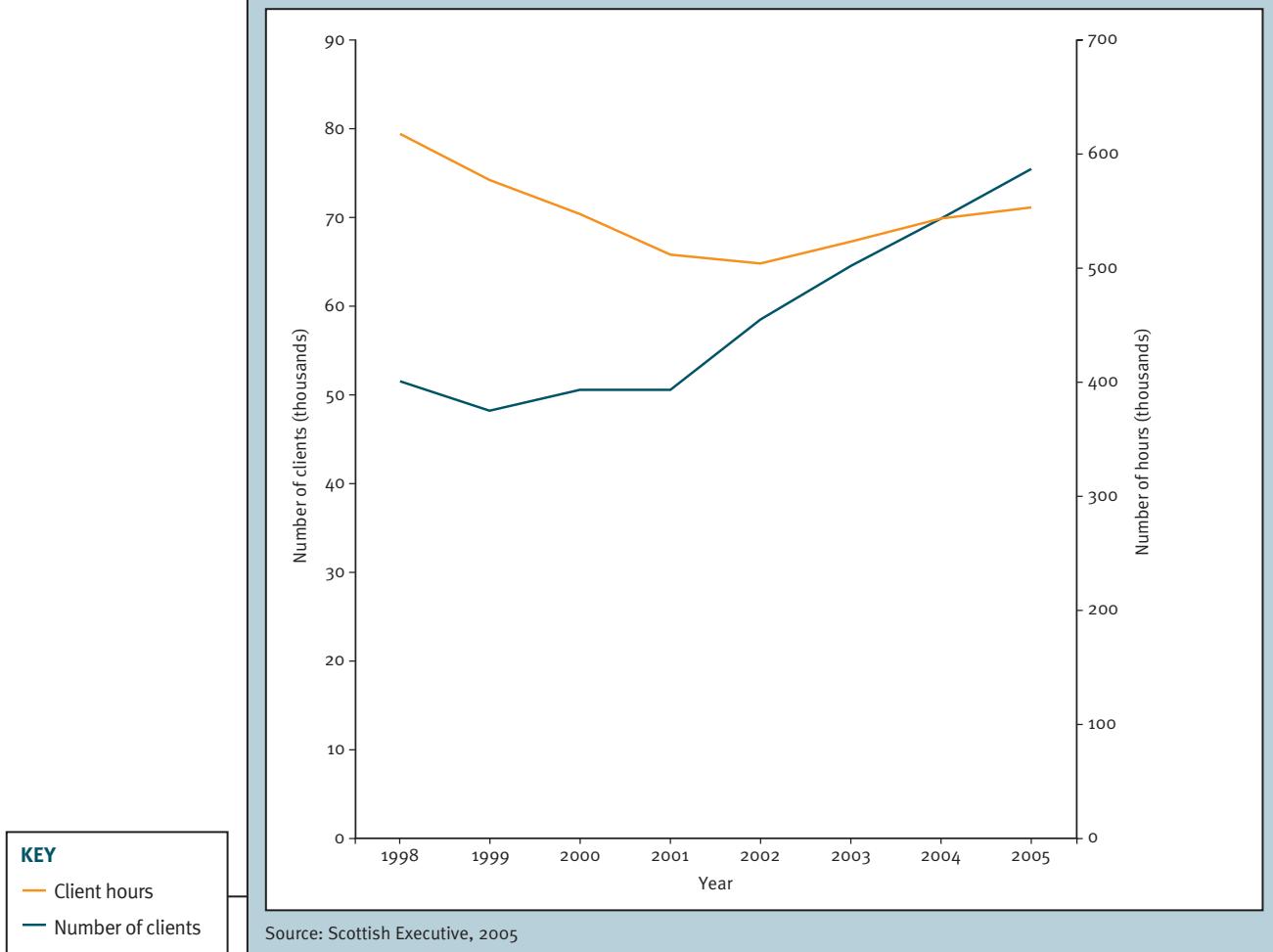
Source: Scottish Executive, 2004e

4). Taken together, these trends seem to suggest that there has not been a deluge of new service users, but that existing users are instead receiving more intensive support.

Late 2004 saw a media frenzy focusing on the amount of money that had been spent on the free personal care policy, with reports that the £126 million annual budget had been spent within the first nine months of the scheme (BBC 2004; Community Care 2004). Scottish Executive figures show that between 1 July 2002 and 31 March 2003, expenditure on free personal care for care home residents was £42.1 million, whereas free nursing care

4

HOME CARE CLIENTS AND HOURS PROVIDED, 1998 TO 2005



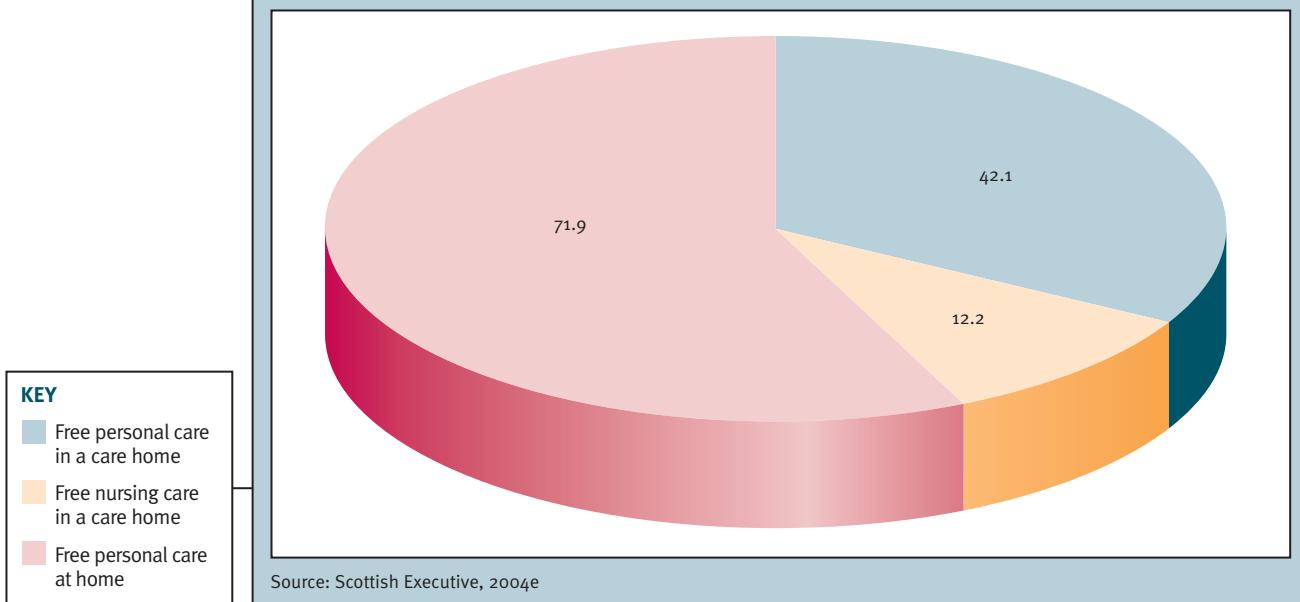
was £12.1 million for the over-65s and £0.1 million for the under-65s. Expenditure on free personal care for home care clients was £71.9 million. Figure 5 shows the expenditure on free personal and nursing care by location.

As demonstrated by the numbers receiving personal care, there are also large differences in the expenditure by local authorities on the provision of personal care (see Figures 6 and 7), although some statistics may be influenced by the fact that some authorities traditionally made no charges for home care services and so experienced less change in their budgets as a result of free personal care.

The difficult nature of accessing accurate data regarding numbers of people taking up services and expenditure has already been highlighted. Furthermore, the Scottish Audit Committee (Audit Scotland 2005) point out that no consideration was given by the Scottish Executive at the outset as to how the impact of the free personal care policy would be evaluated. No success criteria, beyond the level of take-up, that would measure whether the policy was making an impact appear to have been put in place at the outset. The Executive has also not undertaken any measurement since implementation of the policy, making it difficult to evaluate whether the policy is delivering what it set out to do, or

5

EXPENDITURE (£MILLION) ON FREE PERSONAL AND NURSING CARE, 1 JULY 2002 TO 31 MARCH 2003

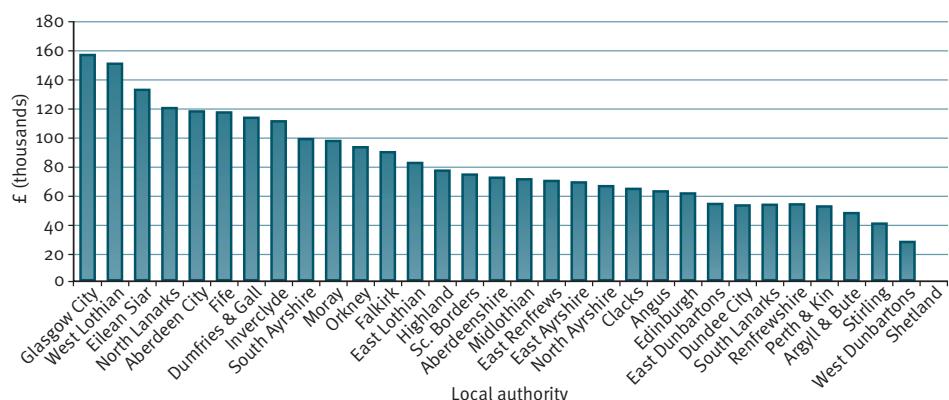


whether it is achieving value for money. Mechanisms for assessing the impacts that community care makes on the life of the service users have also been little considered (Audit Scotland 2000), although this lack of an outcomes focus is not unusual in community care services (either in Scotland or elsewhere).

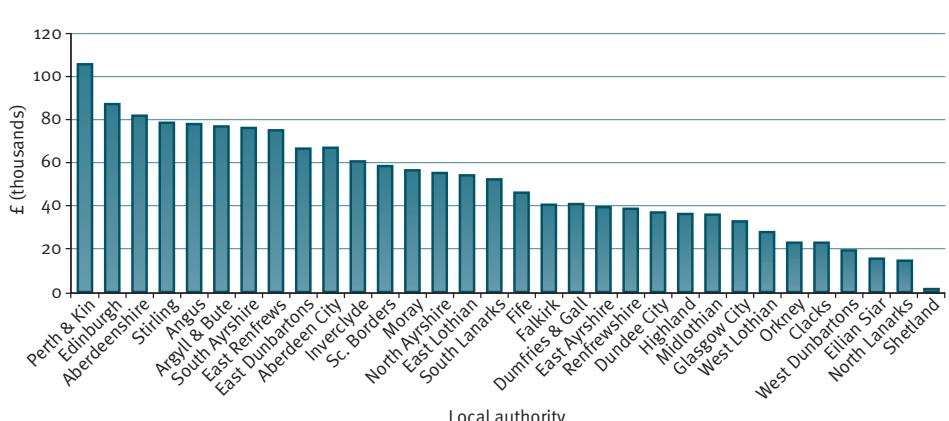
Local authorities were already spending money on personal care prior to the introduction of the policy, but were unable to inform how much of the budget had been spent prior to implementation. This has clearly caused somewhat of a problem, in that comparisons cannot be made with prior personal care spending levels (Audit Scotland 2005). The CDG proposed that any funds transferred to local authorities should be ring-fenced so that they would be transparently used and accountable. However, in practice this has not happened, and there is no certainty that the funds are being used for the appropriate purpose.

The figures given by the Scottish Executive are therefore likely to be incomplete but, as stated above, seem to indicate that in the first nine months of the policy £126 million was spent against an expected budget of £107 million. The Joint Group, in considering submissions from local authorities for funding levels for 2004/5 and 2005/6, acknowledged that in a number of cases the number of self-funding care home residents had been underestimated at the start of the policy by comparison with the allocation basis at 2001 (Scottish Executive 2004b). For the funding period 2004/5 to 2005/6 the Joint Group announced that local authorities would be sharing an additional £10 million for free personal and nursing care as a minor one-off adjustment.

On the grounds that the data used to predict costs may have been flawed (Audit Scotland 2005), potential costs for the future may clearly be much higher than previously predicted. In response to some of these issues, the Executive commissioned the Community Care Statistics Office to run a series of predictions using a range of different assumptions to

6**FREE PERSONAL CARE EXPENDITURE ON HOME CARE CLIENTS PER 1,000 POPULATION AGED 65 AND OVER, BY LOCAL AUTHORITY, 1 JULY 2002 TO 31 MARCH 2003**

Source: Scottish Executive, 2004e

7**FREE PERSONAL CARE EXPENDITURE ON CARE HOME RESIDENTS PER 1,000 POPULATION AGED 65 AND OVER, BY LOCAL AUTHORITY, 1 JULY 2002 TO 31 MARCH 2003**

Source: Scottish Executive, 2004e

obtain an indication of what possible future projections of the cost of the policy may be. Dependent on a number of factors related to demography, technological advances, location of care and levels of informal caring, the predictions of spending on older people's services ranged from 2004 levels of £1.4 billion to £3.5 billion (Scottish Executive 2004a). However, this was largely misinterpreted in the media, where the predicted figure of £2.5 billion by 2020 was stated to be the cost of the free personal care policy alone, and not the total cost of care for older people in Scotland (Valios 2004). What these projections do highlight, however, is the interdependence of a range of community care policies. If community care policies are to be effective and cost-effective, then consideration needs to be given to how various aspects of community care interact.

The Joseph Rowntree Foundation (Wittenberg *et al.* 2004) has also undertaken a series of projections of future expenditure on long-term care services for older people in the UK to

2051. They suggest that figures show the total long-term expenditure for older people is estimated at around £12.9 billion for the UK in 2000. This comprises £8.8 billion public expenditure (£3.5 billion NHS and £5.3 billion social services) and £4.2 billion private expenditure (£1.9 billion user charges for social care and £2.3 billion private purchase of care). Of the total, around £9.8 billion relates to care costs and around £3.2 billion to hotel costs (£1.1 billion publicly funded and £2.1 billion privately funded hotel costs). The introduction of free personal and nursing care in the UK would have an immediate effect in the base year, increasing public expenditure to approximately £10.3 billion. Under the base case this equates to public expenditure increasing from a projected 1.20 per cent GDP in 2051 to 1.45 per cent. It is important to note that these projections do not make any allowance for an increase in demand as a consequence of personal care becoming free.

Key implications

Although free personal care has been widely billed as being a good natural experiment, it has only been in place for a short period of time and it is too early to say whether or not it has been successful. From the beginning, this may have been more of a political and an ethical issue than an economic one, and evaluating the impact of the policy will be difficult given this context and a potential lack of robust financial data. Despite this, the fact that the policy seems to have been welcomed by some sections of the general public and has been implemented across Scotland in a relatively short space of time suggests that the notion of free personal care may be feasible in the short term (if there is sufficient political will) and offers an opportunity to learn lessons from this policy for other national contexts. However, major concerns about the financial sustainability of the policy remain, and the lack of monitoring and evaluation to date has been strongly criticised.

In many ways, it is the community care context into which free personal care has been launched that will determine its likelihood of success. There have been fears that community care in Scotland has been under-funded for some time. Given that the funds for free personal care have not been ring-fenced, moreover, it is difficult to assert that all funds are being put towards the purpose for which they were intended. Furthermore, a situation may result where care homes simply put up their fees for the very self-funders that this policy was intended to protect.

However, there are also a wider range of implications for community care services. If these services are already financially stretched, and are asked to provide more in terms of personal and nursing care, this could potentially lead to the rationing of other services. Under one scenario, it is also possible that a policy of free personal care could work against the desire to keep a greater number of older people at home for longer (as putting someone in a care home can sometimes be cheaper and easier than arranging a very complex community-based support package). However, the opposite may also be true – free personal care may make older people more willing to contact their local authority, and may lead to earlier intervention and more scope for preventive work. In many ways, this is similar to the debate under way in England following the adult social care Green Paper: what is the best way of developing a more preventive approach, and what impact might investing ‘upstream’ have on future costs?

Community care strikes a rather precarious balance, and its effects are felt throughout the entire health and social care community – particularly where there is concerted effort towards ‘whole systems working’ as in Scotland (Hudson 2005). One of the major barriers in forging closer partnership working between health and social care agencies is the fact that one service is means-tested whereas the other is free at the point of delivery. Leutz (1999) describes this as the ‘square peg in a round hole’ problem, where service integration may be frustrated by the different bases of entitlement to those services.

Clearly the implications of this policy go much further than simply whether a certain cohort of the population have to pay a contribution towards their care, and may have the potential to forge closer links between partner organisations. Should more people be able to stay at home for longer supported with free personal care, this clearly has knock-on effects on care homes and hospitals. However, should free personal care prove to push a fragile economy too far, a situation may emerge where there is a rationing of other services which will have a dramatic impact on issues such as the future of some voluntary and independent service providers, delayed discharge and emergency admissions.

At such an early stage and with such little monitoring and evaluation to date, the jury must remain out for the time being.

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Notes

¹ NB The notion of free personal care was not uncontested, and two members of the Commission submitted an additional report contained at the end of the Commission's main findings arguing for the need to means-test personal care.