

Just Care?

A fresh approach to adult services

by Sophie Moullin

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About this paper

This is the second of two reports from ippr's project, 'Care in a new welfare state'. The first report, 'Care in a new welfare society: unpaid care, employment and welfare' (Moullin 2007), is available to download at www.ippr.org.

This paper refers to England, except where noted in the text.

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Executive summary

A just society can be judged on how it supports people who need care to live independent lives. But care for adults has rarely received the attention it deserves.

This is changing. Care needs are increasing. Expectations of services are rising. Uncertainty over the level of support available from the state combines with uncertainty over how much support families can and should be expected to provide. These factors taken together are making care a more important issue, affecting a growing number of people and a wider range of public services. This is an immediate concern for the nine million people in England who report a long-term illness, health problem or disability that limits their daily activities – more than four million of whom are of working age and their families.

There is an increasing realisation that chances for an independent, good-quality life are increased when individuals have choice and control over the services they use. That realisation has the potential to improve care services for adults. But to realise this potential we must think beyond seeing only users of care services in isolation, and beyond the narrow, existing framework of adult social care provision. Adults with care needs use a range of public services across the health, welfare and housing sectors, in addition to traditional social care. Moreover, these services are about more than simply meeting people's personal needs: they are about enabling people to participate fully and equally in society.

How we fund care is a tough question. Before trying to answer it, we need to know what sort of system we want to fund, why and for whom. This paper considers how policy could support the delivery of a new, fairer system of care services. It starts from a central premise: the state cannot support adults with care needs to maximise their independence without better supporting care within families and across communities. This, in turn, means examining how the services that support care work together to enable adults, families and communities to flourish.

We argue that adults with care needs, and their families providing care, could be better supported by giving them greater control over services, and by having greater integration of public services within local communities. We suggest that government develops a framework of desired outcomes from a range of services that applies to all adults with care needs – those self-funding and those funded by the state – and carers. If successfully implemented in combination with other policy changes, this could help to develop a whole system of support for adults that better enables them to achieve independence.

The challenge

Care has long been a collaborative enterprise between individuals, their families, communities and public services. It is the earliest model of 'co-production': a service in which individuals, their families and the state work together. But it is not working as well as it needs to. Based on original in-depth case studies and focus groups, and secondary data analysis, we have identified four core issues.

1. There is a lack of clarity over the outcomes we want for services that support care, and who we want them for.

The vast majority of care services are provided in a private and third sector market, even if they are funded via the state. Those not funded by the state often have inadequate support and experience poor outcomes. And it is a range of services, from health and welfare support to housing, on top of social care, that enables adults with care needs to be independent. Public services and policy therefore need to start by considering the outcomes they want for all adults needing care, rather than thinking only in terms of existing social care services and users.

Carers' outcomes should also concern us. Yet the policy approach to carers has been marginal and out-of-step with the approach to promoting independence for disabled people. Adults want and need independence, choice and control within care relationships and within services. But they also value care and support within their families and communities. Policy needs to reflect clearly that valuing care and promoting independence need to go together.

2. Assessment for care services, and personal budgets, are rarely considered properly within a family context.

Current services for carers are divorced from those provided for people with care needs. In practice this means their support needs to undertake their caring role are frequently unidentified and unmet. When they are, they risk being out-of-step with the approach that gives choice and control to the adult with care needs. Some support currently directed at carers – such as providing ‘respite’ care or short breaks to the cared-for adult – actually serves the person with care needs more directly than it does the carer.

Equally, pilots of personal budgets, which provide cash to individuals in place of care services and are accompanied by self-directed assessment, have shown positive results. But more attention needs to be placed on the family context. Allowing people with care needs to employ their family members using personal budgets can restrict carers’ choices regarding other paid work, and create a barrier to entry into the labour market. It can also tie disabled people into more dependent relationships with family members.

3. Services are not adequately joined-up, which limits the degree to which they can be personal.

Adults with care needs, and their families, usually require support from multiple services. These services – health especially, but also housing and welfare services – are not sufficiently joined-up around the individual, resulting in a complex system to access and navigate. As well as being difficult for individuals, this makes for an inefficient system, and does not allow for services to invest flexibly in response to the needs of a local community. Inadequate information on services also limits choice and control for users over services, and the ability of this to improve service quality.

Despite significant attempts at better partnership working between health and social care, challenges for integration remain. International experience suggests that success will largely depend on shared access points and the ability to pool financial resources.

4. Communities are not sufficiently involved in supporting and shaping care services.

Individual choice, through budgetary control over services, is best supported by having forms of collective voice and influence, peer support and accountability of providers to users. It is also important that we have a ‘public ethic of care’, so that those who need and those who give care are included as equals within society. Routes for collective influence are currently lacking, as are spaces in which to engage with and support each other.

Greater public participation in the care system could also play a part in meeting the need for unpaid care. A recent government review has suggested that there is an untapped and unsupported potential pool of volunteers to support care services.

Opportunities for change: policy recommendations

1. A new system

Develop a ‘universal outcomes framework’

- The Department of Health should lead on the development of a universal outcomes framework for adults, to cover housing, local health services, and the pensions, disability and carers’ service, working in collaboration with the Department for Communities and Local Government (CLG) and the Department for Work and Pensions (DWP).
- This framework should cover those whose care is not funded by the local authority as well as those receiving financial support from the state, and be applied across services. The framework should also bring together the agendas for the range of adults with care needs – older people, learning and physically disabled people, and people with mental health care needs – and those providing care unpaid.
- Drawing on evidence on outcomes and prevention across services, a sensitive performance metric and guidance on good practice for local authorities, practitioners and commissioners should be developed to sit alongside a statement of outcomes.

- The Care Quality Commission should regulate all services, including those in the private and third sector, against these outcomes. The Audit Commission should assess local authorities' performance against them, as part of the Comprehensive Area Assessment.

An outcomes framework of this nature would create a universal system, making local authorities responsible for the outcomes of all adults needing care, including those who fund themselves. It could also help smoothe the sometimes sharp divide between those self-funding and those funded by local authorities. This would also make clear the role for local government in improving the supply and quality in the local care service market.

A focus on outcomes – rather than inputs of resources for care – could allow for public resources to be targeted at those with most difficulty achieving those outcomes, whether that arises from their needs or their financial means. If properly developed and implemented, shared service outcomes and measures across different services including health, housing, and welfare services for adults could also support a more integrated and personal system.

Such an overarching strategy for all authorities would further support and help evaluate existing change aimed at partnership working between health and care services: care trusts, joint commissioning, and the merged health and care regulator. And, rather than potentially distorting targets from the centre, it would also allow for innovation and flexibility in response to local needs and wishes.

2. Individuals within families

Support the use of personal budgets

- Local authorities should offer personal budgets to all adults with care needs that want them, using resources from the reform grant already committed by the Department of Health. Restrictions on the use of budgets to employ family members living within the same household should be introduced. Practitioner support (or brokerage) and peer support and advocacy should be available to all, and practitioners should be able to take a lead professional role as budget holder to support the management of services for those who want it.
- Guidance should be developed, with practitioners' input, to encourage best practice on self-directed or person-centred assessment of adults with care needs, and how to integrate this with a holistic assessment of the carer's needs. Providing a key worker to support a family could help with this.
- Where self-directed assessment for an personal budget with an adult in need of care reveals that the individual has a primary unpaid carer providing 'regular and substantial care' (the current definition used by practitioners), practitioners should also carry out personal, confidential discussions with that carer about his or her support needs. In practice, this may mean a worker spending time with each party privately, and some time with the family together. Guidance should be developed for practitioners for offering such integrated family support.

Introduce carers' budgets

- A separate personal budget for carers should be provided. This should be aimed at carers who are providing a primary, intensive care role, but should be independent of carers' employment status. The budget could be used to purchase whatever support and services they need to enable them to provide care, such as domestic help, counselling, transport or adaptations to their home.
- A carer's budget would be an expense account rather than a 'wage' or replacement income, to help carers with the extra costs incurred in their caring role. The amount of the budget, and eligibility for it, would relate to need and means.
- Current eligibility criteria for Carer's Assessments of giving 'regular and substantial care', or at least 35 hours' care a week in the case of the Carer's Allowance, and the standard Income Support threshold, could be used to establish eligibility for a carer's budget. Working to these

criteria with a budget set at £5000 a year for all, this proposal would cost an estimated £1.1 billion. This is just a 10 per cent increase on current spending on Income Support premiums on Carer's Allowance alone. The budget could consolidate resources spent on carers from various funding streams, including the carer's grant, any direct payments to carers, respite care and potentially Income Support Premiums on Carer's Allowance. This proposal sits alongside proposals made in the first paper in this series, for all for carers out of work to access a single benefit with same rates and access to employment support (Moullin 2007).

3. Services within communities

Provide universal and integrated information

- Local authorities should commission services to provide information and advice on care to all, in a way that suits local people's needs and preferences and builds on existing services, including third sector and user-led best practice. Options for local areas include 'first stop shops' tied to community health services such as polyclinics, care centres housing multi-professional teams, and building on family information and resource centres, user-led organisations and existing good third sector practice.

Simplify assessment

- Authorities should develop an 'Assess Me Once' scheme, to integrate multiple assessments and share information between adult social care, health, and even housing and welfare services, building on the experience of the Department for Work and Pensions' 'Tell Me Once' scheme.

Pool budgets

- Better integration between health and care could be facilitated by allowing the NHS to supply resources for personal budgets for care support to adults with care needs where doing so may prevent hospital (re-)admission, and in 'continuing care' situations, as people are discharged from hospital stays.
- Extending the option of personal budgets across the boundary between health and social care – in particular for those with mental health care needs and some long-term conditions such as mobility problems – could join up and further personalise both health and care services. In these cases, where there is a universal entitlement to services, or where services may be provided under compulsion, we would expect greater use of key workers to hold and manage personal budgets, but users could still choose services in a discussion with their key worker.

Make voices heard

- Public engagement, and therefore service quality, could be enhanced by extending opportunities for users, their families and carers and the wider community to participate in services through the expansion of inspections involving an 'expert by experience' in the Care Quality Commission. The Care Quality Commission should also have a duty to consult with Local Involvement Networks (LinKs).

Improve how we use volunteers

- Local authorities should consider better utilising and supporting volunteers through a 'care share' volunteering project, where adults with care needs could choose volunteers to provide appropriate care, support, 'befriending' and help in advocating on their behalf. Volunteers, who could include disabled people and carers as peers, could gain reciprocal support through a credit exchange. Any scheme should be regulated by the Care Quality Commission and provide appropriate training and checks to ensure it complies with adults' human rights.

Looking at the care system as a whole makes us consider the 'whole' costs, including the opportunity costs, of care. If care becomes central to achieving independence for adults as part of an active welfare society, the answer to how we pay for it should also change. The issue would no longer be a question of how local authorities pay for 'dependent' adults in the current adult social care system,

but instead one of how we can invest in independence across the range of services, and as communities, family and individuals.

By being resolute on enabling people to live independent and included lives, a new system of care services for adults would offer us a progressive vision for public services more widely, and of the families and communities shaped by those services. For the best outcomes for adults, empowered individuals, caring families and communities, and personal public services, all need each other.

1. Introduction

‘A radical rethink is required of the way the state supports people to retain their independence.’ (HM Government 2007)

The Government is right to say there is a need to think afresh about the way services support people to live independently. There has been a shift of approach in how we provide care for the diverse and growing group of people with particular needs: people with physical and/or sensory disabilities, learning disabilities, mental health support needs, long-term conditions or who experience frailty associated with old age (Office for Disability Issues [ODI] 2008). This is reflected in the fact that policymakers as well as practitioners have now started to speak less about *providing* care and more about *promoting independence* for adults with disabilities.

A new focus on independent living

‘Independent living’ means people having choice and control over services and support, and equal access to opportunities, regardless of their care needs. It is about having equal chances to live the lives they want. Driven by a social movement led by disabled people themselves, independent living has recently been picked up in policy, through a cross-government strategy and Independent Living Bill (ODI 2008).

Independent living is also allied with change in public services. Related to independent living for disabled people, the idea that social care services are personal, with the user participating in and shaping services, rather than simply receiving them, has recently risen to the fore (see, for example, Bartlett *et al* 2008). The Government has shown a commitment to the personalisation of adult social care through a grant to local authorities to transform their social care services (HM Government 2007).

Families, services and communities need consideration too

Current analysis and policy with the aim of independence rightly starts with the individual. Too often, however, it ends there too. Little has been said about what achieving independence for adults with care needs means in terms of the responsibilities of families, services and communities. In fact, this recent policy focus on independence for adults with care needs raises three important questions for how we think about families, services and communities.

First, as users are put at the centre of services, where do we place their families or carers? As disabled and older people are given more choice and control, we need to think too about what should be offered to those who care for them. The Government has recently signalled a commitment to transforming social care services for users, by developing a Green Paper on Social Care, and to improve support for carers, through a review of the 1999 Carers Strategy (Department of Health 1999). But the approach for disabled and older service ‘users’ still sits in a parallel policy world to the approach to those who care for them unpaid. This is unhelpful because often the lives, services and outcomes of those that need care and those that give care are entwined.

Second, as adult social care services become more personalised or ‘self-directed’ through personal budgets (which provide cash to individuals in place of care services and are accompanied by self-directed assessment), what other changes are needed across services to enable people to live independently? Adults with care needs, and those providing care in families, need a range of services and support, and how these services work together affects people’s outcomes. However, analysis of care services for older and disabled has often been separate from debate on the design and integration of wider local public services, health in particular. This is limiting because often it is only through having a range of services working together that services can be personalised and people’s independence is promoted.

Third, beyond individual users and unpaid carers, what is the role of the wider community in care, in supporting and engaging with services? By only considering the relationship of individual users with services (for example through individual control over service budgets [Bartlett *et al* 2008]) we risk

achieving independence at the expense of inclusion, focusing on consumer relations to the neglect of caring relationships. In practice, equal access to opportunities for those needing and giving care depends upon collective as well as individual participation in services.

Aims of the paper

Starting from these questions, this paper offers a rethink of how we promote people's independence. First, it considers, as part of a discussion of care services for people with care needs, care that is provided unpaid. By extending a concern with outcomes and choice to those who provide care unpaid in families as well as to those who receive that care, we challenge the current approach and some assumptions around 'informal carers'.

Second, the paper considers 'social care' services within the context of wider public services and community activity that enable people with care needs, and people caring, to live independent and included lives. We argue that the relationships between social care and other services, and between services and local communities, need to be reshaped.

The paper has a central premise: that the state cannot support adults with care needs to maximise their independence without better supporting care within families and communities. This, it shows, requires looking not only at 'adult social care' in local authorities, but also at how a range of services for adults support individuals, families and communities.

A rethink of the role of the state in supporting independence that works with current conceptions about 'users', 'carers' and 'social care services' will not suffice. We must think more radically, about how adults, their families and communities access, participate in and hold to account the kind of services they need to achieve the outcomes they value.

- Chapter 2 sets out the approach taken in the paper, discussing what we mean by independence, who we want it for and how it is affected by care in families and services.
- Chapter 3 presents original case study evidence, adding the voices of carers to the debate and giving a view of the problem in practice.
- Chapters 4-7 structure secondary data analysis and our policy recommendations around different aspects of the care system.
- Chapter 4 considers the outcomes we want for adults and their families, and the potential of an outcomes framework to cover the whole population.
- Chapter 5 examines individual budgets, assessment and support within a family context.
- Chapter 6 examines how local authorities could better integrate information, assessment and resources across different services for adults.
- Chapter 7 explores the role for communities in services, through collective voice in services and volunteering.
- Chapter 8 shows how a whole-system approach to care can help us think about the costs of care.

The paper concludes with thoughts on how care fits into questions of social justice and public service reform.

2. Adults, families and the state: independence and care

How should the state support people's independence? This chapter attempts to answer this question by looking at what we mean by independence, who we want it for, and how it is affected by care in families and services. It sets out the key issues, terms and approach taken in the paper.

Adults with care needs

At some point in our lives, we all need care, services and support to live independently. As recognised by the Government's recent Independent Living Strategy, at any one point some people have additional care needs – including people with learning disability, physical and/or sensory impairments, mental health support needs, long-term health conditions, and those who experience frailty associated with old age (ODI 2008). At the last census, in 2001, nearly one in six of the population (9.5 million people) reported having a long-term illness, health problem or disability which limits their daily activities or the work they could do. Of these, 4.3 million are of working age – more than one in eight of that group.

This paper refers to 'adults with care needs' rather than disabled or older people or a group of adult 'social care users'. Thinking about adults reflects the separation of adult social care from children's services in delivery and professional bodies and the corresponding separation of national departmental responsibilities between the Department of Health and the Department for Children, Schools and Families. Yet thinking only about adult social care users is limiting.

Speaking instead of 'adults with care needs' makes it clear, in line with a social model of disability, that people can be disabled by social structures, services and attitudes as much as by any physical condition (Stanley *et al* 2007). In the Government's strategy for improving the life chances of disabled people, it recognised this 'social model', defining disability as 'disadvantage experienced by an individual resulting from barriers to independent living, education, employment and other opportunities that impact on people with impairments or ill health' (PMSU 2005). This group, like any of the specific 'client groups' of disabled people, involves a wide spectrum and diversity of need, and often crosses over with other client groups.

Related to the above point, speaking about service 'users' does not reflect the nature of the relationship with services sought by the use of personal budgets, or 'self-directed support' (Waters and Duffy 2007). Such innovations have arisen from an 'independent living' movement, which has been concerned with enabling disabled adults to live in their own homes, with maximum choice and control over the support they need to live independently.

Furthermore, adults with care needs also often use or need services other than 'social care' – such as health, housing and welfare services – in order to be independent. Meanwhile, not all older people are disabled or use care services. Fewer than 900,000 adults received council-provided adult social care services in 2006–7 (Commission for Social Care Inspection [CSCI] 2008) yet 2.9 million people under 65 received Disability Living Allowance and 1.7 million over 65 received Attendance Allowance¹ in May 2007 (Department for Work and Pensions 2007). Crucially, it is not always clear to individuals whether their needs fit into health or social care services. This group presents particular challenges for services, seen for example in disputes over 'continuing care', the support people receive when they leave hospital (Gainsbury 2008). For many, long-term health problems and long-term care needs often overlap.

All kinds of care need are increasing. Care needs in people aged 65 and over are estimated to rise by 87 per cent by 2051 from 2002 (Hancock *et al* 2007). The number of very elderly people (aged 85 and over) – among whom need for care is greatest – will rise even faster, from around 1.1 million to

1. Disability Living Allowance (DLA) is a tax-free benefit for people under 65 who need help with personal care or have mobility problems because they are physically or mentally disabled. Attendance Allowance is a similar benefit paid to those over 65 with care needs.

around 4.2 million in the same period. By 2041 the number of disabled older people is expected to double compared with 2002 (ibid).

Increasingly, councils are funding care only for people assessed as having 'critical and substantial needs', as well as property and savings worth £22,000 or less (CSCI 2008). A significant and growing number of people receiving care services therefore do not use services funded or provided by their local authority, and evidence suggests that these people actually often receive a worse service (ibid). A combination of these tightening eligibility criteria and pressures arising from demographic change has led to projections of a shortfall in care between those eligible for state funded services, and those able to finance care themselves (ibid).

While people over 65 are the largest group receiving adult care services, associating social care just with older people can stigmatise younger disabled people, or other people with care needs (for example, resulting from mental health problems or long-term conditions), and, indeed, people over 65 who do not have care needs. Forty per cent of councils' adult social care budgets are spent on people under 65. Viewing adult services as being just for older people can also prevent the transition between children's and adults' services being smooth (Morris 2008).

Taking the above points into account, this paper refers more broadly to 'adults with care needs' rather than 'adult social care users'.

Care in families

Care has long been a collaborative project between individuals, their families and the state. It is the oldest model of what is called co-production: where families and individuals, as well as the state, support an outcome. Those caring in families outnumber those caring in paid social care services by three to one, and 85 per cent of disabled older people living in their own homes receive unpaid care there (Pickard *et al* 2007a). Nearly a million disabled older people rely exclusively on unpaid care, due to tightening criteria for eligibility for state care (CSCI 2008). Census data also shows that 5.3 million people provide unpaid care – a million of whom do so for 50 or more hours a week.

As the number of adults with care needs rises, so will the demand for care provided by the children of older people. Projections show that there were approximately 660,000 disabled older people receiving care free of charge from their adult children in 2005. By 2041, nearly 1.3 million disabled older people are projected to be needing informal care from their children – an increase of around 90 per cent (Pickard *et al* 2007a). However, it is not expected that supply will keep pace with demand: the numbers of people providing care for 20 hours a week or more for older parents are projected to increase by just over 27 per cent between 2005 and 2041 (ibid). Additionally, for younger disabled adults (aged 18–64), a 20 per cent rise between 2005 and 2041 in people receiving unpaid care is projected (Pickard *et al* 2007b). Social changes, such as more people living further away from their families and women expecting to work full-time through the life course, will make caring more difficult and may change patterns of caring. But care in families will continue to play a large and valued role in supporting adults' independence.

Carers are also often users of services. As groups, users and carers cross over: 2.8 million people aged over 50 provide unpaid care and over 225,000 people providing 50 or more hours of unpaid care per week state they are in 'not good health' themselves (ONS 2001). And, of nearly two million adults aged under 75 who are 'permanently sick or disabled', over a quarter of a million provide some care unpaid for other people and 105,000 provide 50 or more hours of care (ibid).

Many see care and independence as opposites. Some thinkers have sought an 'ethic of care' as a distinct value in contrast with a justice based on individual rights and autonomy (Held 2006). But in reality, policy must aim for both. Care is oppressive when it does not consider or promote individuals' independence. And independence without care can be neglectful and therefore disabling. Right through the life course, care affects not only people's quality of life, but also their chances in life. Indeed, disability can be defined as the absence of support and services that people with certain impairments need in order to share in opportunities that other people have (Prime Minister's Strategy Unit [PMSU] 2005, ODI 2008). Research shows that the ability of disabled individuals to both

maintain and regain their independence is strongly related to the quality of their family and social networks in providing social support, if not actual care (Godfrey and Randall 2003).

Care is also valued as highly as independence for many people with care needs. Evidence on older people's preferences shows that people wanted social participation and 'to be in control', but what they valued most highly was having their personal care needs met (Malley and Netten 2007). People also value giving care. Most people say they want to care for partners or parents in their own homes (Opinion Leader Research 2007). Whether one gives care usually depends on whether and how much that person *is able* to care, rather than whether they are *willing* to care.

Giving care can also affect one's independence. Box 2.1 shows how caring at high intensities, providing personal care, as well as access to and the nature of formal care services can affect carers' independence and outcomes too. This paper talks about 'families' to refer to the broad range of personal relationships and partnerships; 'carers' refers to those caring intensively without being paid (normally defined as 'regular and substantial care').

Box 2.1: Outcomes for those providing care

The policy question about unpaid care has been dominated by a concern with sustaining its 'supply'. There is a growing realisation that beyond this we should also be concerned with how providing care can affect people's capabilities. An independent living approach to care understands that the greater a person's care needs are, the more support they need to achieve independence. Similarly, the more intensely care is *provided*, the more support we would expect is needed for carers to achieve a range of positive outcomes for themselves, including choice and independence.

Caring intensity

At the last census, 5.2 million people provided some level of care in England and Wales, of whom just over a million provided 50 hours or more a week. Evidence suggests that providing care at this intensity impacts the most on carers' own outcomes. While on average 40 per cent of all carers report health problems, it is the intensity of caring that is critical. 72 per cent of those caring for 50 hours or more a week reported poor health, as did 61 per cent of those caring between 20 and 46 hours a week (Atkinson 2005). And people who spent 20 or more hours per week caring were twice as likely to have poor mental health than those caring for fewer hours. Only once carers are caring for over 35 hours a week does their risk of poverty become higher than average (Moullin 2007). Informal carers working as sole carer had worse health outcomes than those who belong to a broader care-giving network (Lloyd 1999). The greater intensity with which care is needed or provided unpaid, the more 'dependent' the caring relationship is for either party.

Personal care: 'Personal care' is usually defined as 'care which includes assistance with bodily functions where such assistance is required'. Evidence suggests this is qualitatively different from wider forms of caring, including support and assistance, in terms of the dignity and independence it affords both those that give or receive care in the relationship. On the giving end, participants in an ippr focus group recognised that 'for my mother, it is not dignified for her to be bathed by her children', and that 'he is a young man now, and I don't want to be in the bathroom with him'.

Equality: Those countries that have promoted agency-based formal home care and have higher rates of spending on care, have higher rates of female care-givers (see Figure 5.1). This alerts us to the fact that there are equality-related implications of social care for women – and also for some ethnic minorities – as well as for disabled and older people (see also Lewis 2006, and Moullin 2007).

Economics: A more equal sharing out of care responsibilities would also make economic sense. Those with less intense caring responsibilities are more able to enter paid work and afford home care services; therefore the more caring were shared, the less it would cost to enable remaining unpaid carers to combine care with paid work where they wish to (Himmelweit 2005). In 2041, it is thought that nearly 90 per cent of all those providing intense care, for 20 or more hours a week, will be under the age of 65 and therefore of 'working age' (Pickard 2007b).

The state's role

Care is provided in a mixed economy. Adults with care needs are supported in various ways by families and neighbours in what is called the 'informal' sector; but they are also supported by a range of 'formal' services from the public, private and third sectors. 'The state' also operates at different levels of governance: local government is responsible for the delivery of social and personal care services. Local authorities (LAs) or councils then purchase care from a range of providers – 94 per cent of which are from the private sector and third sector (The Information Centre 2007a).

The costs of care – direct and indirect – are met jointly by disabled people themselves, their families and by a range of public bodies, depending on people's needs and their financial means (Berthoud and Hancock 2008). Forty per cent of older people pay for some care privately and 30 per cent of the total spend on people over the age of 65 is met by private funding (CSCI 2008).

Care is also supported by a mix of services. The needs of many adults with care needs or disabilities span multiple services (Mansel *et al* 2008). Consequently many different agencies or sectors can be involved in promoting the independence of disabled people. Care in community (or non-institutional) settings has been found to require support from a number of agencies, including health, social care, housing, education, employment, transport, leisure, and social security (*ibid*). And inadequate access to public services other than social care can hinder the independence of people with disabilities (PMSU 2005). For example, evidence suggests that people with learning disabilities experience worse access to primary health care than those who do not have these disabilities (Department of Health 2004a).

So as well as through providing and/or funding personal and social care, policy affects adults' (both users' and carers') independence in a number of other ways. These include:

1. Through the provision of **health care**, in both acute and primary services. Older people, and people with learning disabilities and mental health problems (and with long-term conditions) make up a significant proportion of health service users. 'Nursing care', for older people with terminal conditions such as dementia or cancer, sits part in health and part in social care services.
2. Through **local services** such as housing and transport. These have been shown to be particularly important for disabled people, and disabled people experience significant barriers to these services (PMSU 2005). Housing, in particular, plays an important role in adults' independence, such as through the Communities and Local Government's 'Supporting People' programme, and is in many authorities linked to adult social care (Department for Communities and Local Government 2007).
3. Through support for community engagement and routes for community **accountability** for services. User-led support groups, the voluntary sector and social enterprise and community accountability can all be important in enabling disabled adults and carers to remain in the community.
4. **Cost support** through the welfare system. 61 per cent of adults receiving care also receive either Disability Living Allowance or Attendance Allowance (Berthoud and Hancock 2008, based on the Family Resources Survey). And just over half (54 per cent) of adults receiving these 'care-related' benefits report receiving care services. These benefits attempt to compensate people for the costs of disability, although analysis suggests they fall short of doing this fully (*ibid*).
5. Additionally, the state also affects care and people's independence through out-of-work welfare payments and employment services, tax credits and workplace policy, such as rights to leave and flexible working, which the first paper in this ippr programme explored (see Moullin 2007).

These different services show the state operating at different levels over care. In each, complex relations between national and local levels exist in terms of access to and accountability of services, as well as their delivery. Health, support over costs and employment services are all set at the national level and form a universal entitlement. Adult social and personal care and services are based at the local level, and evidence suggests that both means and needs tests vary substantially in different local areas (CSCI 2008). Chapter 6 discusses this in more detail.

Moreover, the way in which the state supports individuals' independence has shifted significantly with the introduction of personal budgets. As chapter 5 discusses in more detail, under personal budgets, individuals will choose and control whatever service support they want, helping to create and re-define a social care service themselves. This significantly changes the role of the state over care.

Those receiving personal budgets are made aware of the whole public resources available to spend on them, and with support choose what they want to spend those resources on. This gives them the option of spending the resource on something other than care. As budgets are given in place of local authority commissioned social services, they are also set to dramatically change what is meant by 'social care' as well as how we think about the nature of using a service. For these reasons, we use the term 'care services' to refer to the spectrum of formal care services delivered professionally, where those providing care are paid, and to recognise that these cut across a number of sectors, levels of governance and services.

Promoting independence in the context of care

In order to be independent we need care and support from our families and from services. But we also need independence within those relationships. Despite this, recent policy and public debates about how the state should promote the independence of older and disabled people have given insufficient thought to the care provided in families and communities and its impact on independence.

The origins of the word 'care' warn us of its costs as well as reminding us of its value. The Latin 'cura' was used to mean both a burden that dragged people down and a power that enables humans to achieve their full potential (Fine 2006). This poses a challenge for the state: how to prevent the former, and enable the latter. A just policy on care would support care to promote people's independence *and* mitigate the costs that caring poses – for those that give it and for those that receive it.

As well as access to financial resources, people's access to care and their control over it significantly affects their inclusion and independence: their ability to participate in society and to live in dignity. This is true for those receiving care and for those giving care. Care can affect individuals' capabilities: their core resources to enable them to realise their human rights, to have equal opportunities to live dignified and flourishing lives (Nussbaum 2006), and to participate in the economy and society. This is particularly so for disabled and older adults (ODI 2008, PMSU 2005, DWP 2005). Care is therefore a legitimate concern for the state.

Taking the above into consideration also leads us to reconsider *how* the state gets involved in care. Independent living, or 'participative services', aims to change the relationship between the state and service user by giving individuals power and choice over their services. This has been developed in reaction to a historical model of care that was thought to give control to providers, not people with care needs. Under a provider-led approach, professionals 'gift' care to passive users. Neither approach gives much consideration to unpaid care in families, a subject that is also often missed out in otherwise comprehensive discussions about social care policy (see, for example, Churchill 2008 or Bartlett *et al* 2008).

By failing to consider care provided in families as a central part of questions about care policy, the role of the state in relation to care has been caricatured as a choice between two opposing models: provider-led, institution-based care or user-centred 'independent living'. As a result, thinking about both care and independence – and how the state supports both 'carers' and 'users' – has been partial and incoherent.

The Government's commitment to independent living – 'that all disabled people, (including older disabled people), have the same choice, freedom, dignity and control over their lives as non-disabled people' (ODI 2008) – depends on care and support from families, a range of public services, including health, social care and housing in particular, and also on engagement by the wider community. But highlighting unpaid care in questions of care services shows that this approach, which is gaining increasing resonance for disabled and older people, sits uneasily with the policy approach taken to carers.

A focus on an ‘independent living’ model of care has quite rightly been a reaction to the problems with a provider-led model of care and institutional care. Table 2.1 gives a simple typology of these two approaches in the left and right columns. Both of these models in fact assume that a significant amount of care is provided unpaid by families – the ‘informal care’ model summarised in the middle. The middle column shows how, when we consider unpaid care at the centre of caring, the traditional approach to ‘informal care’ sits uneasily alongside independent living.

Table 2.1: Characteristics of models of care

Provider-led model	Informal care model	Independent living model
• ‘Service, care’	• ‘Duty, value’	• ‘Choice, control’
• Personal assistance provided	• Family (or friends) provide care	• Personal assistant recruited by consumer
• Patient role	• Dependent role	• Consumer role
• Provider is accountable	• Little accountability	• Individual is self-accountable
• Professional assessment and advice	• Little assessment, support or advice	• Self-assessment, some support and care plan
• Payment through authorities	• Payment to carer through welfare allowances	• Direct payment/personal budgets

Source: adapted from Breda *et al* 2006 and Fine 2006

While the language of independence, rights, equality, choice and control now infuses policy for disabled people, it still remains largely missing from a discussion of support for carers. Policy is built in terms of ‘promoting the life-chances of disabled people’ (PMSU 2005), but when it comes to carers uses the language of ‘caring for carers’ (Department of Health 1999), or worse of ‘sustaining the supply of informal care’ (Wanless 2005). This has meant on the one hand that existing policy on carers has been attacked for putting the interests of carers above those of disabled people (Lloyd 2000); and on the other, that a discussion of support for carers has been divorced from current policy on independent living for older and disabled people. There is a growing recognition that this is unhelpful because their lives, needs and outcomes are often intertwined, and the services that will support them are interdependent (Cook 2007).

The role of the state also relates to concerns about the fairness of the current funding system for care, and its future affordability. The Government has committed itself to a major review of how social care is funded (Department of Health 2007a). But before we can make decisions as to how much the state should fund care services, and the relative contribution of individuals and families, we need to be clearer on the outcomes we want from the care system as a whole, and the roles for individuals, families and the state in the system. We should not think simply about the state *providing* care or individuals *consuming* care services: we must also ask whether services are ‘caring’. Are they respectful of, and personal and accountable to, individual adults, families and communities?

This paper does not make a case for a specific funding option for care service, but asks the vital question: what kind of a system do we want to fund? The next chapter starts answering this question by looking, through case studies, at how care, as by provided by the state and by family members, is experienced in reality.

3. The experience of care: case studies

This chapter presents the stories of four different kinds of caring relationships.

Just as they have sometimes been ignored in analysis of how the state promotes independence, family members providing care have often been excluded from research and policy analysis of how they affect people with care needs (Carers UK 2006). To redress this balance, and to provide an in-depth understanding of how care and care services are experienced in reality for people, ippr shadowed people providing care in families for adults with a range of care needs.

These studies only reflect the researchers' understanding of carers' stories, and it should be borne in mind that these may not be the same as those of the carers or the people they care for. The case studies are included as whole stories as they seek to acknowledge the importance of people's caring relationships and people's relationship with care services and the wider community. ippr also undertook focus groups with carers in families to inform our policy analysis and quotes from these are used throughout the paper. A detailed methodology can be found in Appendix A.

Case study 1: Caring for Sarah

Laura and Emily care jointly for their mother, Sarah, who is 83 and suffers from severe osteoporosis and asthma and is largely confined to her bed. Sarah came to live with her daughters in 2004 when her husband, who until then had been her primary carer, died.

Although Emily was very clear that she wanted to take over her mother's care, Laura was less convinced. She had a good career that was important to her and was not sure that she and Emily could take on the additional responsibility. What persuaded her was the small amount of input that the family had had in her father's care in the run-up to his death when he had been in intensive care for five months. 'We had no say in how he was treated,' says Laura. 'I just couldn't go through that again.'

Arranging for Sarah to live with them was not straightforward. Sarah lived in Essex and Laura and Emily rented a house together in North Yorkshire. They were told by Essex County Council that they would not be able to take any of Sarah's equipment with them because it belonged to the council. North Yorkshire Council would not give them any equipment until Sarah had been assessed. This meant that they had to buy a wheelchair for the journey, and Sarah had to be assessed by her new council before she was eligible for a comode.

North Yorkshire Council was also unwilling to provide services for Sarah when she first arrived as it wanted to see how she settled in before doing an assessment. Laura and Emily therefore had no support for two months. During this time and also while her father was ill, Laura was unable to work. Her employer refused to give her a leave of absence so her only alternative was to ask her GP to sign her off sick. While they were waiting for the support services to start, however, the situation became more difficult. Laura was asked to come back to work and she simply could not. In the end rather than discuss future flexible working arrangements, Laura's employer dismissed her with three months' pay.

Putting the necessary care for Sarah in place required a number of assessments from the local GP, social services, the occupational therapist and physiotherapist. Laura and Emily's greatest frustration is with the fact that each element of care is so separate and there has never been a holistic assessment of all the family's needs. As well as being carers, Laura and Emily are coordinators of their mother's care, often making calls to several different agencies in one day.

One of the most frustrating times for the family was at the end of 2006. Just after Christmas, Sarah fell out of bed during the night. It was clear that Sarah was not able to safely make it out of bed by herself any more so Laura and Emily requested a hospital-style bed to make it easier to manoeuvre Sarah and a hoist to help her out of bed to the toilet. While the bed arrived quickly it took three months for the hoist and sling to arrive. In the meantime Laura and Sarah regularly hurt their backs getting Sarah in and out of bed. The bed, furthermore, was not suitable for Sarah's needs as it was not multi-directional, meaning that Sarah was uncomfortable and developed bed sores. The council

also refused to provide arms for the bed initially, claiming that their reason for wanting bed arms (to keep Sarah from falling out of bed) was a human rights violation. It was only when Laura and Emily argued further for this – giving the reason that Sarah had difficulty breathing at night meaning that she needed to sleep upright with her head to the side – that the council relented.

The financial situation is also complicated. Emily is currently unable to work and receives Incapacity Benefit and Disability Living Allowance. This means that the family is largely dependent on Laura's salary. However, since Laura was forced to leave her job in 2004, she has been working part-time for a charity and has taken a significant pay cut as a result. Both Laura and Emily receive resources from carer's grant [an allocation of local authority funds] which can only be used for themselves and not for respite care or any services for their mother. Laura uses hers to get help with domestic chores around the house and Emily to fund trips to an osteopath to help the back problems she has developed from lifting Sarah.

Because the family has some money from the sale of Sarah's house they currently do not qualify for full support from the council. This means that if Laura and Emily want to take a respite break (which they try to do about four times a year), they have to pay two carers around £1,000 for the week. Having some additional support is vital for the family because Sarah's needs are such that neither of the daughters feels comfortable leaving her on her own. This means that every excursion out of the house needs to be pre-arranged and agreed between them even if it is just a quick trip to the supermarket.

Laura and Emily have explored other services offered by local charities and have found them to be well-meaning but very limited in what they can offer. The 'sitting' service offered by a local charity, for example, is just that. The sitter cannot do anything to help Sarah, such as assisting with getting her to the toilet or making her a cup of tea. They have also found that the limited services on offer are also very inconsistent. One sitter who they had come to rely on for a short Saturday slot left the charity and they were not told about her departure or found a replacement. Their experience has made them understandably nervous of the services on offer.

The family have had a continuing care assessment but do not qualify because they are currently considered to be coping. Laura and Emily are frustrated that the assessment only looks at their mother's health needs and, in their words, 'does not consider the health needs of the carers who deliver her care day in, day out'.

Although the family is managing at present, they are concerned about the future and what might happen if Sarah gets worse and they cannot cope. Laura feels that the current system does not plan and is not flexible enough to allow for change. She is also scared that if they did have to take the decision to put Sarah into residential care, they would not be able to afford it.

The family's approach to Sarah's caring needs is very open and inclusive. Laura and Emily ensure that Sarah makes decisions with them about her care. There are limits, though. For example, the carer's assessment would have taken place in front of Sarah if they had not specifically requested that it did not, which Laura in particular would have felt uncomfortable about; they do not want Sarah to feel guilty about their need for an occasional break.

Laura and Emily say that many of the services and care practitioners they come into contact with are professional, friendly and very well-intentioned but unable to help the sisters in the way they would like because their hands are tied by the system. Laura's part-time position with a carer's charity means that she is involved in the policy debate on this issue. She thinks that in many ways it is hard for policymakers to create a system that can respond to everyone's individual needs but is frustrated that the current system often bears no relation to reality. For Laura and Emily an improved system would be one that is not so piecemeal, can look at the holistic needs of individuals and their carers and respond as one organisation rather than several.

Since this shadowing took place, Sarah has died.

Case study 2: 'Daniel's army'

Jill is 62 and cares for her son Daniel who is 26. They live in a cottage in rural Norfolk. Jill has cared for Daniel all his life.

Daniel has profound learning and physical disabilities. He has an immature brain and a gut disorder. He suffers from both epileptic and non-epileptic seizures and has severe pain in his gut, which is partly due to the drugs that he has been given to counter his epilepsy. Daniel finds it difficult to sleep as he is in pain most of the time and this means that Jill often has very little sleep too. Jill also suffers from arthritis.

Jill has lived in the town since before Daniel was born. Until 1996, she worked as a PE and Special Needs teacher in the local school, which she enjoyed very much. As a result, she is well known in the town, having taught many of the locals or their children at one time or another.

While Jill was teaching, Daniel went to a school for people with profound learning disabilities in the bigger nearby town. It was very difficult to balance caring for Daniel with having a full time job. The school was not as supportive as it could have been; when Jill missed a meeting, one colleague told her that she needed to take a time management course. Jill retired in 1996 because the combination of having a job and not sleeping was making her really ill.

Between 1996 and 2000 Jill did not have any help with caring for Daniel. Then in 2000, she realised that she really could not cope any more. At this point Daniel had not had a social worker for four years. Jill rang the Carers helpline and they put her in touch with a local charity that runs schemes to support carers and people with care needs. The process of getting help was not straightforward. The charity's staff member who carried out Daniel's assessment subsequently left the organisation, at which point there was a complete breakdown of communication. However, eventually both Social Services and the charity became involved again.

Since Daniel turned 14, Jill has said that she wants him to be able to live independently of her. She wanted him to go to residential college and then to have his own home. In order to enable this to happen, Jill managed to get tripartite funding from the Learning and Skills Council, Social Services and the Health Service for Daniel to have a residential place at the Centre for Young People with Epilepsy. Daniel took up this four-year place when he was 20.

For the first year that Daniel was attending the college, he appeared to benefit greatly. He had physiotherapy every day and started to walk properly for the first time. As a result Daniel is no longer in a wheelchair and his mobility has improved. However, he is still very unsteady on his feet and, since he left the college, he has not been able to receive physiotherapy through the NHS. This is because there is no nearby physiotherapist trained to work with people who have learning disabilities. Jill says that if he were able to get regular physiotherapy, this would benefit him hugely.

After Daniel had been at the college for over a year, the locum consultant changed. The new consultant seemed unaware of the health regime that had been originally set up by Daniel's doctors at home. Jill says that this new locum regarded her interest as 'interfering'. This new consultant dramatically changed Daniel's epilepsy medication at the severe expense of his holistic health. Daniel was suspended from the college pending an enquiry. However, both Jill and the charity Mencap felt that the enquiry did not address these issues satisfactorily. Jill felt she had no choice but to remove Daniel from the college. He came home two years in to his four year placement. In retrospect, Jill feels that the college accepted Daniel because she had secured funding for him, but was actually not equipped to meet his level of need.

Jill and Daniel have been living together since Daniel came back from the college. Jill is twice-divorced and is still close to members of both families. Their house is never quiet. Since 2004, a group of 50 friends, relatives, care workers and professionals have formed a 'circle of concern' for Daniel. They call themselves 'Daniel's Army'. Jill has friends who regularly help with preparing Daniel's food and house work. Food preparation is paid for under the direct payments scheme. She pays for help with the house work herself.

Jill looks after all Daniel's needs from washing him, monitoring his medication, dealing with his seizures to pointing out aeroplanes in the sky, because Daniel loves aeroplanes. She also keeps copious notes recording his toileting, nutrition, seizures and a daily log recording everything that happens with him. Because Daniel can only eat very specific foods (he cannot eat meat, fish, oils or wheat) Jill makes all his food for him. On days when Daniel does not have day care workers, Jill hardly sits down.

Daniel is involved in various activities including Riding for the Disabled and swimming. Riding is good for Daniel because it helps him with his balance and confidence. Daniel loves being in the water when they go swimming. Jill really enjoys this too because she has the opportunity to have a swim herself, one of the few physical activities that her arthritis allows. They have access to a car through the Motability scheme, which is paid for by Daniel's mobility allowance. This is really important to them because it enables them to do all these activities.

Financially, things are not easy. Jill has a retirement pension and state pension and therefore she is not entitled to any benefits. She feels angry that, since she reached pensionable age, her pension has been offset against her Carer's Allowance, yet this is the time when she most needed both. She says: 'How dare they give with one hand and take by the back door in a way that nobody understands. In fact, they've taken part of my pension. They've no right to do that.'

Daniel receives Disability Living Allowance (DLA) and Incapacity Benefit. Much of this goes on the specialist food that he requires. Jill currently spends about half her pension on Daniel. For example, she pays for the riding and swimming herself. Daniel is also entitled to money from the Independent Living Fund (ILV) but Jill has not taken this up because, if she did, Daniel would lose half the care component in the DLA. Jill says that, with the DLA, she can choose how to spend the money whereas with the ILV, there are specific rules about how the money should be spent. Jill had wanted money from the Independent Living Fund to spend on physiotherapy for Daniel but she was told that she could not spend it on this. She has been told by Social Services that the ILV is the only way that she would be able to top up on financial support for Daniel.

Jill has been concerned about what will happen to Daniel financially when she dies. She has set up a discretionary fund in his name and her estate will feed a 'Daniel Fund'. They will ensure that his fund has just below whatever the Government allows so that he will still be entitled to his benefits. The Government accepts this as a system for leaving money to people in Daniel's situation.

Over the years, Daniel has received care from a number of different organisations. At present Daniel has 24 hours per week of day care from the Elizabeth Fitzroy Trust. Jill really likes their ethos because they try to involve Daniel in everything and their approach emphasises helping Daniel to develop a better understanding. Someone from a charity comes twice a month on a Saturday to take Daniel to a Mencap day centre. This is great for Jill because it is the only point that she gets any time off at the weekend. The problem is that there is only one charity carer nearby working with people who have learning disabilities. If this care worker goes on holiday, there is no one else to take Daniel to the day centre. However, the charity is addressing this issue.

Until recently, Daniel was having night care assistance from an agency. However, Jill has recently ended their contract due to a number of problems including incorrect invoices and sending carers to replace people who had never come. This has been very upsetting for Daniel as he had become quite attached to his two carers. It also means that Jill is presently getting virtually no sleep. However, this situation is constantly changing.

Daniel currently sees a gastroenterologist, a urologist and a neuropsychiatrist as well as an excellent GP. He has recently been referred to a nutritionist specialising in learning disabilities. Because of the experience at the college, Jill is determined that, if Daniel lives somewhere independently of her, he should stay within his medical catchment area and that his nutritional needs should be taken seriously by the people looking after him.

Jill has as little to do with social services as possible. She says that social services are used to dealing with dysfunctional families and families where abuse is happening rather than families that are

'functional' but coping with learning disability. Jill finds that she needs to get approval from social services for everything and that they are very critical. One example is that social services disapproved of Jill giving Daniel his medication with food because they claimed that this was 'hiding' it from him. Yet Daniel can see the drugs perfectly well and he waits for her to mix them in with his food at the end of his meal.

Jill says that the problem with Social Services is that 'they have a lot of power but not a lot of money' and that they need to be much more open and transparent. For example, she has found that they do not make her aware about options for Daniel that are more 'expensive'. In Jill's experience, Social Services are good at providing knee-jerk reactions in emergencies (such as when her arthritis was so severe she could not get out of bed) but not at long-term planning. While in general she gets on well with individual social workers, she says that the system is inflexible; they are unable to adapt the rules or respond to individual needs. For example, they take the view that everything should be 'age appropriate' but by this they mean chronological age. Jill feels that they ought to gauge things by Daniel's mental age. For example, they talk about Daniel having choices, ignoring the fact that Jill has told them that Daniel cannot choose.

Another example of the inflexibility of the system is that Job Centre Plus regularly sends Daniel letters, inviting him in for interviews and saying that they can find him work. When Jill has contacted them to explain Daniel's situation, Job Centre Plus said that they automatically send these letters to everyone on these benefits and will continue to do so.

Jill feels very strongly that Daniel needs to get used to living independently of her in preparation for a time when she is no longer around. She has been trying to get Daniel his own home for five years. Daniel needs his own toilet because of his severe gut problems and he also needs a bidet for washing.

Daniel has been offered three different 'placements' and they have all been inappropriate in different ways. For example, last year Daniel was offered a placement which involved living with four others, totally supported. The running of the housing was contracted out by Social Services to a company. Jill was told that one of the other residents had autism and one had epilepsy but was unable to find out what the difficulties were for the others. The company said they could not give more information about the other residents for data protection reasons. Then one of Jill's friends who is a care worker warned her not to let Daniel go in. This friend had found out that three of the residents were people with 'challenging behaviour' (which Jill understands to mean people who have mental health problems and are aggressive or violent through no fault of their own). Jill says, 'Daniel would be like a sitting duck in that situation.' The company also claimed that Daniel could not possibly have his own toilet or a bidet in his room because he has to be treated like everybody else and because it was their policy to 'move people on at some point'. Jill had thought that this would be a semi-permanent home for Daniel. When she explained this, the company responded by saying that this 'choice' would be up to Daniel. Yet Jill says that Daniel is unable to understand or make a decision like this.

When Jill withdrew Daniel from this placement, the situation became so stressful that she nearly had a second breakdown. Social services put her under a lot of pressure to change her mind. She thinks that this is because Daniel is classified by the Government as critical and therefore he attracts lots of funding.

Jill is hopeful that Daniel is going to receive one of ten places on a new independent living scheme between the county council, a housing trust and social services. They have got funding to top up the gap between the funding that Daniel attracts and what is actually needed. If he does not get one of these places, she is going to take equity on her house and she hopes to come to a private arrangement with the housing trust.

As a result of these experiences, Jill says that she feels cynical about the motives of social services. She feels that, if Daniel's care were left to social services, it would kill him. However, Daniel's Army provides a really important form of support in their lives; Jill knows that there will be a group of close concerned friends looking out for Daniel if anything happens to her.

Jill's relationship with Daniel is open and loving. She knows and understands him better than anyone. But she also feels that Daniel cannot be utterly dependent on her, for his own good.

Case study 3: Letting her down?

Michael, 85, and Julia, 79, have been married for 57 years and live in North London. In 2001 they were on holiday in Spain when Julia had a nasty fall down a wheelchair ramp. The resultant head injury caused severe frontal lobe damage.

Although Julia had to spend five nights in intensive care and a further seven on a ward in Spain immediately after her accident, it was not evident at that stage that the fall had caused any lasting effects. Once back in England, the couple went on as normal for almost four years. Gradually, however, the frontal lobe damage Julia sustained has affected her more and more and she now has fronto-temporal dementia. Julia has almost no verbal communication and her mobility is severely limited. It is unclear just how much information she is able to absorb and retain but she is able to smile and laugh and, occasionally, say 'yes'.

Michael is Julia's main carer and they live together in the same house in which they have been for 50 years. Although Michael has considered moving them to wardened accommodation he feels it is far more of a comfort for Julia to be in the home she knows so well.

Michael receives limited formal help. He has a morning care worker, Louise, who Michael describes as his 'lifeline'. Louise comes in every morning to get Julia out of bed, change her incontinence pad, wash and dress her. Michael says that he would not trust anyone else to look after Julia. Louise leaves by around 10:15 and then it is just Michael and Julia for the rest of the day. They receive very few visitors and Michael does not go out to see friends anymore. Almost all of Julia's day is spent in front of the television.

When Julia needs her incontinence pads changing or needs to use the toilet, Michael has to help her out of her chair and up the stairs. This is not easy, particularly as Julia has put on weight due to her inactivity. A few times in the past Julia has fallen. When this happened, Michael was unable to pick her up by himself so he either had to call an ambulance or ask someone on the street for help. He has now had a rail fitted along Julia's side of the bed so that she cannot fall out of it.

Once a week another care worker visits for a few hours so that Michael can go out and buy the weekly shopping. This is one of the few times that he leaves the house aside from going to the bank occasionally when Louise is around in the morning.

Michael says that he would really like another care worker to come in at night but he cannot afford it. He currently pays £13.40 an hour for Louise's daily visit. He has refused to be financially assessed by social services because he 'resents that fact that I'd have to bare everything I've got to some clerk somewhere'.

He also does not think that he would be able to find anyone else that he would trust to look after Julia. He says that in the past he has found that many of the care workers he has been sent do not know what they are doing and that the care they give to Julia is not personalised: 'all you are to them is a figure, a number'. He thinks that before anyone is allowed to work as a care worker they should be required to shadow a carer first.

In addition to his limited formal help, Michael also receives valuable support from a carer's charity. His support and advice worker visits him once a month for an hour, but they also speak frequently on the phone. The two of them have built up a real rapport and it is clear that Michael appreciates this support. This connection is Michael's main way of getting the information he needs about the services available to him.

Despite this support, Michael has refused access to a number of the services that are available to him and Julia. He says that this is because he wants to be completely comfortable with the way that Julia is being looked after. However, at present, Julia has no physical activity at all and her only source of stimulation is the television. On occasion, Michael has taken Julia out to the supermarket with him but this is very difficult given her limited mobility. He also does not like taking her anywhere else because he fears the embarrassment of the incontinence pads failing.

Before Julia's illness, Michael says that the couple were great entertainers and would frequently have

large dinner parties showcasing Julia's celebrated baking skills. Michael misses the way that they used to live and does not want to start doing things now that they did not do as a couple before. This means that, for him, the idea of day centres or organised trips, are out of the question.

Michael has been discussing the idea of moving Julia to fulltime care with his support and advice worker. This is a very difficult decision, though, and at the moment Michael is very clear that he will look after Julia for as long as he can; he is deeply devoted to his wife and feels that putting her in a care home would be letting her down.

Case study 4: caring at a distance

Liz, 64, lives in London and is a non-resident carer for her mother, Anne, and her uncle, David. Anne and David live within walking distance from each other in a town outside London about 30 miles from Liz's home. Anne is 94 and has lived in sheltered housing since 1990. She has lost her short-term memory and is also physically frail, with urine incontinence. David is 82; he has been widowed for eight years and lives alone. He is physically able but, following a minor stroke 14 years ago, he also has problems with his short-term memory.

Anne was completely independent until she was 83. In 1996 as she was convalescing following a deep vein thrombosis, her short-term memory suddenly deteriorated. After Anne left hospital, she had care workers for six months. However, for nine years after this she managed without any formal carers; she lived at home with David visiting regularly while Liz cared for her from a distance. As Anne and David's memories have gradually worsened, this arrangement became increasingly difficult to maintain.

Since 2006, Anne has had care workers three times a day except on Saturdays, when Liz is the carer. Anne also attends a day centre twice a week. David continues to manage without any formal care or support. However, he has a very confused sense of time, which makes it hard to manage daily routines and tasks.

Liz currently visits her mother and uncle every Saturday, and on other days when needed or if Anne is unwell (Anne had several falls in the last year). When she visits, Liz will bring Anne's shopping for the week and any shopping that David needs. She will do the laundry, cleaning and organise their medication. She also deals with any other practical issues that arise, including ensuring that David has enough cash for the week. When the weather is good enough, she will try to take her mother out somewhere.

During the rest of the week, Liz cares for her mother and uncle from a distance. On days when Anne is at home, Liz will call mid-morning, at lunch time, after tea time and at bedtime. During these calls, she talks Anne through drinking, eating and taking her medication. She also does memory exercises with Anne over the phone. When Liz calls at bedtime she will talk Anne through going to bed. She will check whether Anne's incontinence pad has lasted and, if Anne is wet, she will talk her through changing the pad and her clothes. Anne finds this very difficult and the bedtime call can take 45 minutes.

David finds it hard to manage a daily routine for his meals and medication, collecting his pension or visiting Anne. He often forgets to lock his front door when he goes out, which makes him vulnerable. Liz calls him regularly in order to remind him to take his medication, to check whether he is able to visit Anne, or remind him of any appointments that he has, usually with the GP. He needs reminders of all these things at the time they are due to happen – even half an hour too early will be no use as his short term memory is so poor.

Liz feels strongly that Anne's individual carers are all very caring people and give Anne gentle and patient care. However, she says that the lack of continuity in Anne's formal care causes many problems. For example, because different care workers come to do Anne's evening meal on different days, they will often give Anne the same thing to eat every night. Liz often ends up throwing away food that has been left to go past its sell-by date. Anne had Meals on Wheels for a while but it did not work out. Staff used to leave the food in the kitchen and Anne would not remember it was there. Ensuring that Anne eats well is therefore a particular concern for Liz.

Since Anne's care workers have been employed by agencies rather than social services, they have had less time to spend with Anne per visit. In particular, Anne's bedtime care workers are very overworked and they have started coming as early as 6:30pm. Anne finds it difficult to change her incontinence pad herself and if they come and change her pad too early, it often will not last through the night.

Liz has also found that there is a lack of coordination between health and social services. GPs feel that it is not their job to administer medication and social services refuse because they say it is a medical job. The care workers used to remind Anne to take her medication. However, the care manager has told Liz that they cannot do this anymore. Liz feels this is insurance-driven rather than being about meeting Anne's needs. She says: 'If I weren't there to give her [Anne] her medication, I think she'd be in care. It's as simple as that. And it's a job that takes me 15 minutes to put it in the box at the weekends and then a couple of phone calls every day.'

Anne currently receives some support through her sheltered housing. This has good communal facilities but there is a lack of activities for those people who find it difficult to leave their flats on their own. When Anne first moved in, there was a permanent resident warden who would help to organise activities and would visit residents who found it hard to leave their flats. However, this has now changed and sheltered housing officers work on two-week rotations. Because the wardens are moving round every two weeks, they do not get to know the residents and Liz thinks that they cannot really tell who is most vulnerable. She also finds them very hard to contact.

The day centre that Anne attends twice a week is very crowded and Liz says that although the staff are very caring, lack of resources mean that the service they provide is not that good. Liz has visited and found rows of elderly people sitting in chairs with bingo and dominos the only activities on offer. Liz thinks that the centre could be much more imaginative; Anne would really enjoy activities such as cooking or surfing the internet.

Caring for Anne and David has greatly affected Liz's life. She retired from her job three years ago although contractually she could have continued working for longer. She found that, although her employer was very supportive, her responsibilities towards her mother made it difficult to undertake work commitments, as she did not want to let people down.

Liz finds caring physically tiring; she is constantly on her feet when she is visiting David and Anne. She also finds it emotionally tiring; in her working life she deliberately chose to work in a role that was extremely varied. Now she is trapped in a situation with an extremely rigid routine. It can also be frustrating and upsetting. There was a time when Anne would forget that there had been a visitor as soon as they left. It was very upsetting for Liz to think that Anne must have felt so abandoned. In some ways, Liz finds David more of a worry than Anne, because his unreliable memory makes him irrational and he is very open to exploitation.

Anne's care workers are funded through social services and she contributes £20 per month. She receives low-level attendance allowance and two small occupational pensions from herself and her husband along with some small savings. Liz does not receive any financial support for her role as a carer. She thinks that she would probably not be entitled as she is not a resident carer but she has not checked this. Liz wishes that she had arranged to have power of attorney over her mother's finances before Anne's memory deteriorated. She says that once there is memory loss, it is very difficult to arrange this.

Liz feels that she could improve Anne's quality of life if they lived closer to one another. However, she is hesitant about moving Anne for many reasons, the most important one being that she does not want to move her away from David, who is Anne's only friend and one of the few people that she can converse meaningfully with. Liz is currently thinking about what to do if it reaches the stage where Anne cannot live at home anymore. Anne would prefer to stay in her flat for as long as possible or stay with Liz rather than going into a care home. Liz's flat is not physically suitable for Anne but she is aware that once Anne goes into a home, it would be very difficult to get her out again if she were unhappy or not well cared for.

Liz says that she does not know what would happen to Anne if Liz were unable to care for her. She feels that it is important to recognise the difference between caring for children and caring for older people; children will eventually grow up and leave home but when caring for older people, things can only get worse, and there is no hope of a happy ending. She wonders what happens to those individuals who do not have this kind of family support.

General observations from our case studies

The above analysis aimed to look at care in families and services as it is experienced 'on the ground'. While each of these stories raises particular issues, a number of key themes can be drawn out as follows:

Families: caring relationships

- Caring is valued by those who care, and is often part of loving relationships but at the same time it can also be frustrating, exhausting and demanding.
- There is a sense of duty and emotional motivation in caring; while it is hard work, it is not seen as a normal job.
- Carers often have a role coordinating services and formal care on behalf of the person they care for.
- Beyond primary carers, or immediate relatives, there is a role for a wider group of people in providing care and support.
- Few of these carers have had their own needs assessed.
- There are often tensions between what carers want and need and what the person they care for wants and needs.
- Carers often feel that they have substantial expertise in understanding the needs of the person they care for. This can be both because they have in-depth, holistic knowledge of the person's medical history and because of their intimate relationship and insight into the person's personality. This can be both positive and negative.

The relationship between families and services

- Services are limited in both what they offer and in who can access them and who is eligible for them. Poor quality of formal services puts additional pressure on carers.
- Services and policy affecting disabled people, and their carers, are fragmented.
- Carers need to be able to trust in the quality of care services and staff.
- Lack of continuity of services and in individual care workers assigned to a person can be a problem.
- Assessment for services seems invasive and burdensome.
- Services are highly complex and time-consuming to access and manage.
- Services tend to address the needs of users and carers in part rather than looking at either the users or carers or the relationship between the two holistically.

Communities: wider relationships

- Caring in families and the use of care services are rarely experiences that are shared outside the relationship and are often marginal or hidden.
- Those who have wider support from friends and are integrated into the community have a better experience of care.
- Beyond primary carers, or immediate relatives, there is a role for a wider group providing care and support.

These key findings are broadly consistent with our additional focus group-based qualitative research, and a recent large-scale consultation with carers undertaken by Opinion Leader Research (OLR 2007). The case studies helped frame the key questions for our detailed secondary analysis and inform the discussion of policy questions in subsequent chapters.

4. Promoting the independence of the person as a whole: outcomes

Having analysed in chapter 2 what the main issues are, and reflecting on the experience of the problem on the ground as explored in the case studies in the previous chapter, we now set out a proposal for an outcomes framework covering a range of care services for adults.

A person is more than the sum of their different service needs. Achieving independence means more than an absence of dependency. It is about being included, and participating as equal citizens. Chapter 2 showed how thinking about adult social care ‘users’ is limited for a number of reasons; instead we should recognise all ‘adults with care needs’, and also be concerned with the outcomes of those that give care. Instead of trying to tightly define the groups of ‘users’ of a given service, we should start from what outcomes we want adults to achieve.

Outcomes for adults

Starting from what outcomes we want for all adults helps us improve on the current policy approach for local authority adult social care users in three central ways.

First, it enables us to consider what range of services, and what kind of services, are needed to enable people to be independent. Second, it allows us to recognise integrally those who provide care unpaid – both as partners in achieving outcomes for adults with care needs, and as individuals whose own outcomes matter. Third, it makes care a universal rather than marginal issue, but still allows us to prioritise those who have most difficulty achieving various outcomes, because of the intensity with which they need or give care.

We propose that the Department for Health lead the development of an outcomes framework for adults to act as a basis for agreeing local arrangements in care services for adults. An accompanying framework of performance metrics for adults should clearly show the relationship between outcomes, aims, targets, indicators and inspection criteria. As successful implementation and the workforce will be critical to improving delivery against outcomes, government should develop a systems framework for the outcomes with professional and user groups.

The outcomes and their phrasing should be developed through consultation with adults with care needs, carers, the general public and professional and third sector groups. The outcomes for social care listed in the last Social Care Green Paper (Department of Health 2005b) could be streamlined into five key, clear outcomes that would set a universal framework for adult services. An example of a set of outcomes for adults would be:

1. **Quality of life:** enjoying good physical and emotional health, security and access to services
2. **Dignity and equality:** not being subject to abuse, staying safe, having equality of access and treatment within services and society
3. **Choice and control:** having maximum independence and choice and control over services
4. **A positive contribution:** participating and being included within families, the community and wider society
5. **Economic wellbeing:** having access to resources sufficient for achieving the above, including the ability to meet costs arising from specific individual needs.

Advantages of a universal outcomes framework

An outcomes framework covering all adults, and shared across local services, could help address five key challenges, delivering a set of benefits.

First, it would provide a universal framework, but within that allow for resources to be targeted at those with most difficulty achieving these outcomes, whether due to the level of their need or to their having limited means. Evidence from the social care regulator shows there is great confusion over the basis on which people are eligible for support, and inconsistency and unfairness in who gets support both within and between local authorities (CSCI 2008).

Second, a focus on outcomes for adults generally rather than specific client groups would better allow for flexibility around boundaries between different groups and changes in people's needs and circumstances and enable services to be personal to individuals. This would be because it would not assume a static or single group of 'social care users' and 'carers', and would be further in line with moves towards individuals defining their own ideas of care and support. This, through use of individual budgets for example, may be much broader than what is currently defined as a social care service.

Third, an outcomes framework would recognise the contribution of a range of services – health, housing and welfare as well as social care – in promoting outcomes for adults with care needs. It would help focus the range of services and professionals working with and for adults around a clearly articulated statement of the outcomes we want for adults as individuals. As chapter 6 details, service divides, particularly between health and social care, hinder the effectiveness, including cost-effectiveness, of each service. An outcomes framework would be more in line with an approach centred on people, not services.

Fourth, at a more technical level, a focus on outcomes can improve the way quality in services is measured. It is thought that clarity on outcomes from a service supports the development of related performance and output measures in care services that account for quality. Currently, there are inadequate ways to measure either quality of services or the impact of care services on individuals' life chances and quality of life, and therefore to effectively target resources, including investing in preventative services. The Atkinson review of public sector productivity found that measures for care could be improved. It proposed that care services develop output measures adjusted for quality, which take account of the attributable incremental contribution of a service to the outcome (Atkinson 2005).

Focusing on outcomes such as independence, rather than outputs such as the cost of care per hour, could also encourage and reward a more preventative approach to service investment. Moreover, some features of *how* care is provided – in a way that respects dignity and places choice and control in the hands of the disabled person – are valued outcomes in themselves. Promoting and rewarding such outcomes in services requires sensitive performance measures. A number of reviews suggest quality measures of the contribution of care services to various outcomes can be effectively drawn up (Netton *et al* 2002, Malley and Netten 2007).

Finally, a universal framework would communicate a strong national priority agenda for care and its important role in promoting adults' independence, and therefore social justice. Social care services, and support for older and disabled people, have been seen as a marginal part of government policy (Kendall and Harker 2002), lacking the visibility, status and priority of health and education services with clear institutions and national agendas (Platt 2007).

Chapter 6 looks in more depth at how the outcomes framework would work at the level of local delivery.

A policy parallel: Every Child Matters

The parallel in policy is the Government's 'Every Child Matters' (ECM) approach to children and young people's services. This was developed to articulate a new, shared approach to children and young people's services across a number of service agency and professional divides. The basis was a recognition in government of a need to understand the welfare of the young person as a whole, and to prevent them falling between different services. Below we summarise the experience of this approach.

The Every Child Matters green paper was published alongside the formal response to the Lamming Inquiry into the death of Victoria Climbié. It built on work to strengthen preventative services, in particular to increase the focus on supporting families and carers – the most critical influence on children's lives, to ensure necessary intervention takes place before children reach crisis point, protecting children from falling through the net, and addressing weak accountability (see ECM website, www.everychildmatters.gov.uk). It involves integration at various levels, including strategy

(planning for services and resources), governance (through Children's Trusts), processes (such as assessment) and delivery (including co-located services and multidisciplinary teams).

Successful joint planning, commissioning and funding can help to reduce overheads and generate economies of scale, bringing greater efficiency. Inspection against the outcomes framework is also thought to target activity on clear outcomes for the person, unconstrained by service boundaries and preventing duplication and reducing burdens on those inspected. There is a two-way process between the framework and practice. In inspection, for example, the framework lists the key judgements to be made by the inspectors; and the framework, in turn, connects judgements to national indicators and targets (DCSF 2008).

The experience of an outcomes framework for children also points us to two caveats that should accompany such an approach. First, the implementation of the framework across local areas requires time and in terms of improved outcomes much depends on frontline staff delivery and local leadership. Second, and related to the previous point, the performance metrics have to be developed sensitively, in a way that reflects users' and practitioners' experience in service delivery, and allows for innovation in the system.

We believe that the above offers broad lessons to be applied to developing a successful outcomes framework for adult services.

Box 4.1: Recommendation 1: Develop a national outcomes framework for adults

- The Department of Health should lead on the development of a national outcomes framework for adults, but work in collaboration with the Department for Communities and Local Government (CLG) and the Department for Work and Pensions (DWP), to cover housing, local services and the pensions, disability and carers' services.
- Drawing on evidence on what outcomes matter, and what best supports the achievement of outcomes, across services (including support that prevents poor outcomes) a sensitive performance metric and guidance for local authorities, practitioners and commissioners should be developed in collaboration with those groups.
- The Care Quality Commission should regulate all services, including those in the private and third sectors, against these outcomes; and the Audit Commission should assess local authorities' performance against them, as part of the Comprehensive Area Assessment.

The next chapter looks at how these outcomes could be supported in practice and within families through personal budgets and assessment. Chapter 6 details how a universal framework could facilitate a council-wide, multi-service approach to care at the local delivery level.

5. Considering the family as a whole: budgets and support

Having discussed the need to think about the outcomes we want for all adults, this chapter asks: how can those outcomes, independence and care be promoted in practice within families?

We examine a major policy change that aims to improve independence and other outcomes for adults: personal budgets (which give eligible people resources in place of services commissioned in a local authority) and their accompanied form of assessment that allows for disabled people to direct it themselves (self-directed assessment). We pay particular attention to the potential impact and role of these policies in terms of unpaid caring in families.

Personal budgets: background

The UK government recently committed a £520 million reform grant to 150 local authorities to develop personal budgets, signalling a commitment to their roll-out (HM Government 2007). Here we provide some background and explanation of how they work.

Personal budgets give eligible people with care needs (including those arising from old age, learning disabilities and physical disabilities) a personal budget, with a statement of the total amount of resources to be spent on them, enabling the recipient to then choose the services and support they need. Personal budgets are often also referred to as individual budgets; they differ, however in the funding streams that make up the budgets. Individual budgets are drawn from multiple funding streams on top of adult social care – five in the Department of Health’s pilots – while personal budgets have been drawn largely from adult social care funds and the independent living fund. Either a practitioner or directly employed ‘personal assistant’ can hold the budget for the person, or the recipient can buy the services directly themselves. Both the Prime Minister’s strategy ‘Improving the life chances of disabled people’ (PMSU 2005) and the Department of Health’s white paper ‘Our Health, Our Care, Our Say’ (Department of Health 2006) express a commitment to the use of individual budgets in adult social care.

As part of promoting independent living, the aim of personal budgets is to give people with care needs choice and control over their services. This is an outcome in itself, but it is thought this would also drive greater respect, dignity and other aspects of quality of care services, and efficiency in social care.

Personal budgets reached the second stage of their evaluation in 2007, having been piloted by ‘in Control’ (a social enterprise working in partnership with a number of local authorities). In these pilots, budgets were accompanied by support related to seven principles. These are having the rights to:

- Independent living (they get the support they need to be a citizen)
- A personal budget (they know how much money can be used for their support)
- Self-determination (if someone needs help making decisions, decision-making should be made as close to the person as possible, reflecting their preferences)
- Accessibility (a clear and open system of rules)
- Flexible funding (I can spend resources on me without unnecessary restrictions)
- Accountability (the person and the authority have a responsibility to explain their decisions to each other)
- Capacity (disabled people, their families and communities must not be deemed incapable of managing their own support or contributing). (Hatton *et al* 2008)

Personal budgets, wherever they have been piloted, have allowed an option of receiving services in-kind and professional support for budget holders. Authorities have retained some role in monitoring the standards of care for users: social workers and practitioners have a role providing advice, information and support, and in many cases actually hold the budget on behalf of the user, while allowing them to make decisions over what services and support they want.

The number currently receiving personal budgets in the UK is still very small, although it has grown rapidly under the pilots (from 60 people in 2005 to 2,500 by the end of 2007).

Direct payments were a forerunner to individual budgets, but unlike personal or individual budgets only used resources from local authority adult social care, and could only be used to purchase care services. Evaluation evidence shows that numbers receiving them was low, and varied significantly between local areas. This was due partly to cultural and attitudinal barriers among professionals, under-developed local market and local support, and scarcity of resources in the system (Fernandez *et al* 2007). This points to the importance of development of a 'whole system', as chapter 6 outlines.

Support for people using personal budgets

In the pilots, almost everyone (96 per cent) had some support in planning their budget. Seventy-one per cent had help from a paid professional (older people and people with physical disabilities being most likely to have this), and 18 per cent paid someone directly, specifically for this purpose (almost all people with learning disabilities). Nearly half had support from family and/or friends. Two-thirds of people had support from just one source, whether that was paid or informal.

This suggests that professional support (or brokerage, as it is sometimes called) will remain important under a system driven by personal budgets. As one carer in ipp's focus groups put it: 'I can't deal with the forms, tax and so on – it would be easier if someone could coordinate everything and just tell us what we are entitled to.'

The support role includes the following:

- Clarifying the person's needs and expectations, especially in line with eligibility criteria and Fair Access to Care Services (FACS) guidance
- Identifying and applying for funding from a range of sources, including government and non-governmental sources
- Negotiating and liaising with support and service providers
- Monitoring and evaluating support. (Hatton *et al* 2008)

Peer as well as professional support has emerged as important to personal budgets' success: a range of websites, events and organisations have started up for this purpose (Hatton *et al* 2008). User-led organisations to support people's independent living have arisen and are important in providing advocacy on behalf of and advice to people with care needs (Morris 2006), and government has now committed to supporting a user-led organisation in every local area (ODI 2008).

Outcomes for adults with care needs

Early evidence from the evaluations of personal budget pilots shows them to produce high satisfaction among those that use them, as well as reducing costs in some cases (Bartlett *et al* 2008, Fernandez *et al* 2007). Evidence arising from the In Control pilots indicate the impact of personal budgets on each of the social care objectives set out in the white paper, 'Our Health, Our Care, Our Say' (Department of Health 2006). Box 5.1 (next page) summarises this.

Choice and control for adults is an outcome in itself. Self-determination is seen to be critical to the success of similar individual budget schemes abroad. In the Netherlands, and in experimental schemes in the United States, while those receiving care via a personal budget have similar levels of quality of care as those who are referred to an agency, they report less dependency because they have control over when and by whom their care is provided (OECD 2005). This impact far outweighs any potential risk to the quality of care – the pilots in the US found no adverse effects on users' health and safety, although support from family members to the user of the budget was important in this (Foster *et al* 2003).

Box 5.1: Evaluation of personal budgets

The In Control pilots have produced the largest data set available on personal budgets, based on evidence from 196 people in 17 local authorities (two-thirds of whom were new to personal budgets, having had one for only six months or less).

Since starting on personal budgets, with associated support, in the In Control pilots:

- Nearly half of people (47 per cent) surveyed reported improvements in their general health and wellbeing (only 5 per cent saying their health had got worse)
- Over half of people (55 per cent) reported spending more time with people they liked (only 3 per cent saying this had worsened)
- Over three-quarters (77 per cent) said their quality of life improved (one per cent reporting it worsening)
- Nearly two-thirds (63 per cent) said they took part in and contributed to their communities more (2 per cent saying they took part less)
- 71 per cent reported no change in how safe they felt (one per cent saying this got worse)
- 72 per cent said they had more choice and control over their lives
- 59 per cent said their lives had more dignity (no one reported lessening dignity)
- 36 per cent thought their economic wellbeing had improved (only 5 per cent felt it had got worse).

Source: Bartlett *et al* 2008)

This data applies across the range of care needs: only 20 per cent of the group analysed had physical disabilities, over half (58 per cent) had learning disabilities, and 13 per cent had care needs arising from old age.

Note that a separate evaluation has been commissioned by the Department of Health into individual budgets in 13 pilot sites, which was unpublished as this report went to press. In these pilots, in contrast to the personal budgets described above, individual budgets use five different funding streams in addition to adult social care.

Impact of personal budgets on the market and costs

Personal budgets have been shown internationally to stimulate a market for professional home-care services, including short breaks and respite care. In the In Control pilots, 82 per cent of people changed the services they used. This suggests that personal budgets, through which individuals commission (or buy) services themselves, would change the market in services from that in operation currently, from which local authorities commission (or buy) services, towards more closely matching support with the needs or wishes of the individuals.

The In Control pilots reduced costs of schemes by an average of 10 per cent. Excluding those cases where people's conditions worsened, the cost savings are almost 15 per cent (Bartlett *et al* 2008). Of 102 cases of personal budgets, 53 per cent received less money, four people's total resources stayed the same, and 45 per cent got more money (*ibid*). Due to the small numbers currently receiving personal budgets, it is too early to see evidence of reduced transaction costs but it is thought that personal budgets could bring efficiency savings through being more sensitive to particular needs, reducing the costs of assessment and case management, and through integrating budgets and being innovative in their use of resources (Hatton *et al* 2008).

This is a context in which increased productivity in social care without enhanced innovation and reduced transactions costs is difficult to achieve, largely because quality in care is measured by the labour costs and time for which it is provided. This means that as wages rise for care labour rise, so will the cost of care services. So care services will not share in increased productivity in the rest of the economy without further lowering wage costs (and care workers are already among lowest paid workers and agencies suffer from chronic recruitment and retention problems, affecting service quality [Skills for Care 2007]). Treasury data shows that productivity for adult social care services fell by an average of 2.1 per cent between 1996 and 2005 (ONS 2007).

Impact of personal budgets on caring in families

Personal budgets for people with care needs have important implications for carers too, but these have received little attention. Our qualitative work with carers raised three important questions: what is the nature of the family's and carers' role in managing the budget? Can carers in a household be 'employed' through them? And, how do we support costs and needs that are specific to carers?

Managing budgets

Often carers manage budgets, and this has implications for their administrative burden, as well as the choice and control of the person with care needs. Budgetary control, either through a personal budget or a direct payment, will be legally extended to adults who 'lack capacity' or have 'fluctuating capacity' to articulate their choices through the Health and Social Care Bill currently passing through Parliament. Significant concern was raised about personal budgets among carers ippr spoke to, particularly those caring for a person with a learning disability. For example, carer said: 'I don't have time to deal with that, on top of the caring. It would take up too much time to find carers, and what if the carers are ill? I don't want that responsibility.' Carers also made assumptions about the ability of the person they care for to choose their own care: 'She can't choose; I'd have to choose for her.' This obviously has implications for the independence and control of people with care needs.

Employment through budgets

The pilots of personal budgets have no restrictions on spending, other than that they must find sufficient care. This potentially allows family members living in the same household as the person they care for to be employed by that person. This risks changing a caring relationship into formal employment, which can make the relationship more dependent – for both parties.

Carers ippr spoke to felt strongly about this: 'It would be like robbing from my mum', one said. While carers want financial support and recognition, a 'wage' was not seen to be appropriate: 'It is not about what I get paid, I don't want to be a carer, I never asked to do this, I just want someone to help me with the burden.' Caring for loved ones carries a sense of duty and value, which makes it different from formal employment. A mother who cares for her disabled adult son felt strongly: 'I'm not a carer, I'm a mother. If you are a mother, how can you call yourself a carer, it is your duty to care for your child.' The people ippr spoke to also felt that the term 'carer' was wrongly confused as being equivalent to a paid care-worker: 'The paid carer chooses to do it, and I don't choose to do it.'

'Employing' family members to care is also problematic for people with the care needs or for practitioners to monitor, and 'It is difficult for government officials to insist that a daughter be fired' (Weiner 2003: 16, cited in Glendinning and Kemp 2006). The experience of personal budget schemes elsewhere in Europe indicates real risks associated with personal budgets being used to support care through providing 'wages' to informal carers, discouraging the participation of women and older

Box 5.2: The experience with personal budgets in Austria

In Austria long-term care allowances for the cared-for person were introduced in a way that allowed them to be routed as wages directly to the informal carer, with some unwanted results. Half of recipients of the allowance bought some formal care services, but inadequacy and paucity of services meant it was rational for older or disabled people to choose to have more, rather than less, informal care. This was shown to decrease the choice they had over unpaid care, and to make it more difficult for carers to be employed formally outside their home (Kriemer 2006). Incentives to use family members as carers far outweighed those to purchase or even articulate demand for formal care services (Glendinning and Kemp 2006).

The introduction of the personal budget led to an increase of more than 60 per cent in total public expenditure on long-term care (Kriemer 2006). Further, because many personal budgets were used to pay informal carers, the long-term care allowance in Austria failed to stimulate the market supply of formal care services for older and disabled people, and the costs of formal services rose (*ibid*). Belgium and the Netherlands have similar schemes; relatives must enter into a legal labour market relationship with the budget holder and have no independent entitlement to financial support for the care they provide. In both countries similar impacts to those in Austria have occurred (Breda *et al* 2006).

workers in the labour market, and further risking the financial sustainability of the system (Lundsgaard 2005). In Flanders, for example, 48 per cent of personal budget holders paid informal carers, 68 per cent of these living in same household, and 76 per cent of whom were women (ibid). Box 5.2 above details further European evidence, from Austria.

Supporting carers' costs

Allowing people to combine paid work with caring over the long term, and achieve financial independence within the household, is important to those giving care, as well as to those receiving it (see Moullin 2007 for a discussion of welfare payments and workplace policy for unpaid caring). Table 5.1 shows how a number of different personal budgets schemes work in relation to carers in families in Europe and the United States. Rates of employment for women aged between 45 and 64 are used as an indicator for caring because it is this group of people who are most likely to be providing care unpaid.

Table 5.1. Personal budget schemes in selected countries: how they work

Country	Scheme	Can family carers be 'employed'?	Share of pop'n aged 65+ on scheme (%)	Share of pop'n aged 65+ receiving public home care (%)	Spending per user [1] (%)	Female employment rates [2] (%)
Sweden	Carer's salary	Yes up to age of 65	0.1	9.1	101	37.4
Austria	Cash allowance for care	Yes	14.8	14.8	n/a	23.5
Germany	Cash allowance for care	Yes	5.7	7.1	53	26.5
Norway	Care wage	Yes	0.3	18	57	35.8
Netherlands	Personal budget for care and nursing	Yes but not if living with care recipient	0.8	12.3	57	24.3
United States	Cash and counselling	Yes	2.8	Experimental, involving 1000-2000 older persons in each state	60	31.8
UK	Direct payments [3]	Yes but not if living with care recipient	0.04	20.3	13	30.0

Notes

- Spending per user: given as a percentage of private consumption (roughly equal to average disposable income per capita)
- Female employment rates are for women aged 45-64 in 2003, based on national labour force surveys

All information refers to the most recent year available (2004 for payment levels, 2003 or 2 for the number of users)

- Direct payments: UK data is given for direct payments, as data refers to period before which individual budgets were evaluated in the UK.

Source: Adapted from Lundsgaard 2005 based on OECD data

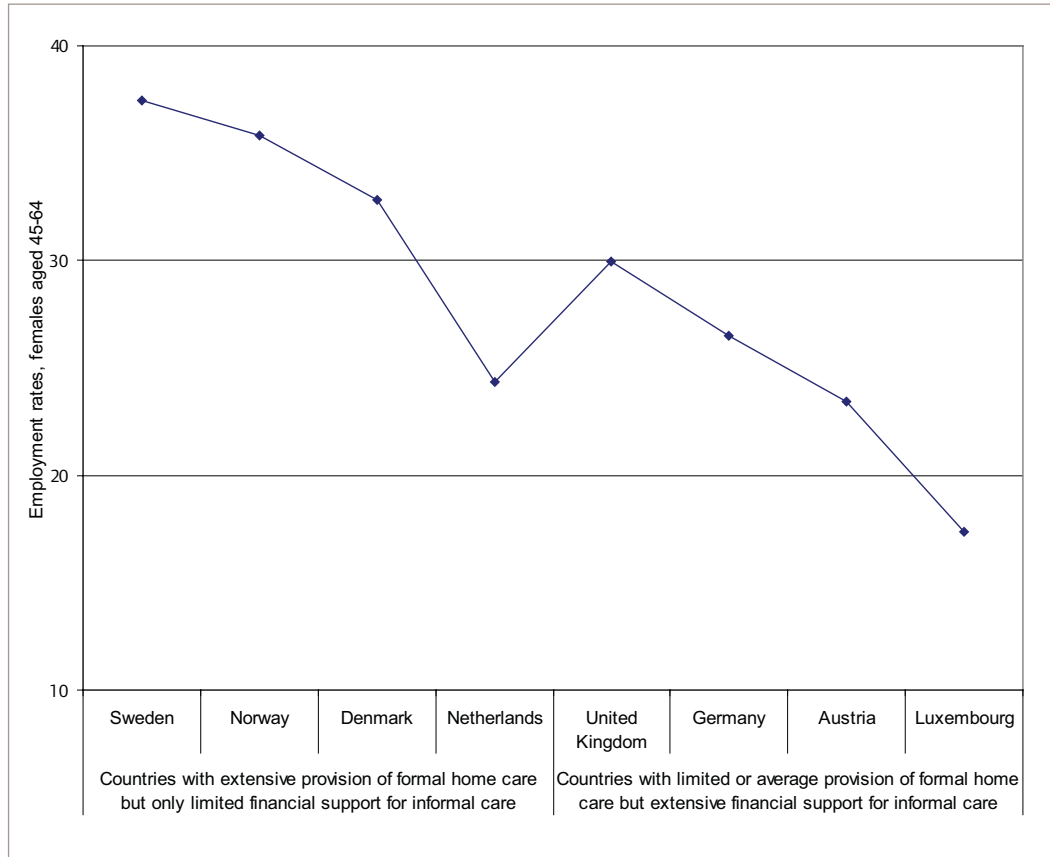
Figure 5.1 compares the employment rates for women in those countries that have promoted agency-based formal care homes (Netherlands, Norway, Denmark and Sweden), with others that have supported people being cared for in their own homes through financial support directed at 'unpaid' carers via payments to the person needing care, who then 'employ' their carers (Austria, Germany and Luxembourg). The UK is classified as having extensive financial support for informal care compared with other OECD countries, in the form of support provided in the welfare (or social security) system,

such as Carer’s Allowance and associated premiums that are paid by the state rather than by family members (see Moullin 2007). The graph indicates that those countries with extensive support for formal care have higher rates of middle-aged women in paid work than those that rely on giving financial support to carers.

Figure 5.1: Employment rates of females aged 45-64 in different European countries

Note: ‘formal home care’ refers to care provided in an individual’s own home and does not include residential care

Source: Lundsgaard 2005, OECD comparative data



A personal budget for carers

If allowing family members to be employed as carers through personal budgets can affect the independence of both parties, how, then, should we meet the particular costs to carers, and services specific to carers, while promoting independence?

Caring has costs beyond those resulting from not being in paid employment. This is reflected in existing support including Carer’s Allowance, associated premiums on Income Support and, in some local authorities, the carer’s grant and direct payments to carers. To simplify and improve this support to carers, we propose that in addition to budgets for adults with care needs, carers also receive a personal budget to spend on whatever support and services they need. This could come in the form of an annual grant, and be awarded to people assessed as caring intensively (for more than 35 hours a week) and as being the primary carer. The budget, given in cash direct to the carer, could be spent on whatever helps carers fulfil their caring role, such as domestic help with shopping or cleaning, making adaptations to the home, and transport costs.

A carer’s budget would be separate from any out-of-work (income replacement) benefit². It could consolidate existing resources spent on financial cost support to carers, for example through income support premiums to carers, carer’s grants and direct payments to carers. In May 2007, 221,700 people received income support premiums to carers, at an estimated cost of £1 billion annually

2. Note that ippr also recommends carers be able to access a single working age benefit; see Moullin 2007

(Moullin 2007). For carers not in paid employment the budget would be additional to any income replacement payment. The amount of the budget and any means test for eligibility for the carer's budget should be modelled in relation to existing practice in both the welfare and social care systems. As an indication of costs, if the criteria were set to be the same as for income support, and if the budget was £5000 annually, we estimate the costs would be £1.11 billion. This is 10 per cent more than the spending on carers' income support premiums, and does not include other costs of services and support to carers given through social care services.

Benefits of a budget for carers

A personal budget for carers would offer important benefits over either allowing users to pay family members in the household out of personal budgets or simply assuming that carers' support will be met from support directed at the user. These are fourfold. First, it would be a resource independent from the income of the person they care for, to spend on the carer's own support needs, therefore avoiding the creation of financial dependency within the family. Second, it would be paid based on the intensity with which they care, not employment status, therefore avoiding creation of disincentives to combine care with paid work. Third, it would be a clear single entitlement, simple to access and administer. Fourth, it would be consistent with giving choice and control to users, while recognising the particular role of individuals providing care intensively.

Assessment of care needs

Alongside personal budgets, self-directed or person-centred assessment is seen as a central part of creating personal and effective care services. This reflects the acknowledgment that 'disabled people are best placed to take the lead in identifying their own needs and in identifying the most appropriate ways of meeting such needs' (PMSU 2005). A shift from provider-led 'tick-box' assessment towards self-assessment, or person-centred assessment, has occurred alongside the pilots of personal budgets, as a core part of achieving independence for people with care needs. Assessments based on tight eligibility criteria were one of the barriers to effective implementation of direct payments (Fernandez *et al* 2007), seen as a forerunner of individual budgets. Care managers found it difficult to make the shift from assessing whether someone is eligible for a particular service to assessing what their overall needs are (CSCI 2004).

How the needs of families are identified and affect eligibility in assessment is a question that remains in self-directed assessment. Carers feel ignored in assessment and allocation of services: 'they treat us like we don't exist', as one carer in our focus groups said. At the same time, in assessments of eligibility for services, local authorities take into account support from family members, such that having someone caring for you unpaid may disqualify a disabled person from eligibility for care services (Department of Health 2003).

It is thought that assessments that do not take into account care provided in families (called a 'carer-blind' test) are likely to distribute limited resources in a more regressive way. Including support for those with unpaid carers would spread resources more thinly, meaning some people without family members providing care would receive less support than they would otherwise. But not accounting for the needs of intensive carers in families can lead to poor outcomes for both those giving and receiving care. As one participant in ippr's qualitative research put it: 'If you have a carer working 24/7, you would think they would have the common sense to say that carer needs some support.'

Carers have had a right to a separate assessment of their needs since the 1994 Carers Act, but in 2005-6 only a quarter of carers who cared for someone who received care services were offered an assessment (CSCI 2008). And only 6 per cent of carers received carer-specific services (The Information Centre 2007b). The evaluation of the 1999 Carers Strategy concludes that: 'successive legislation has failed to systematically underpin support to carers with in-depth and holistic assessment of their needs' (Seddon *et al* 2007: 3). Further, it found that 'practitioners pay limited attention to carer willingness to continue caring once their ability to care has been established' and that 'very few carer assessments lead to active care management' (*ibid*: 2). When surveyed, 41 per cent of new carers were unaware of what entitlements, services and information were available locally (Yeandle *et al* 2007d). The problem of identifying carers' needs for support is all the more difficult as

many people move in and out of caring responsibilities, and many people do not identify themselves as 'carers'.

By considering the support needs of carers and users separately, there is a risk that services directed at carers will not be consistent with the choices of the person with care needs. For example, 'respite' care, or short breaks, is currently the central service for supporting carers (Department of Health 1999, Royal Commission on Long-Term Care 1999). However, this service can produce tensions between those giving and those receiving care, some of whom dislike the idea of respite (Arksey and Glendinning 2007). Even respite care and breaks that do improve carers' welfare remain services essentially provided for care recipients, not givers (Pickard 2004).

At the same time, our qualitative research with carers found that caring at high intensities with no support in many cases restricted carers' own choices. As one man caring for his mother put it: 'She is my mum, and I love my mum. But like this, it is destroying our relationship. So if you ask what I want, I want my life back.' Older people are reported to be particularly likely to want only a close relative to look after them; refusing external services can also reflect the care recipient's desire for 'normality', or denial that external formal help is needed (Arksey and Glendinning 2007). This restricts carers' choices, such as over whether they combine paid work with caring. Over 40 per cent of new carers said that the refusal of the person they care for to accept other services impacts on their ability to work (Yeandle *et al* 2007a).

Giving support to families

The practice of assessing and identifying support needs should move away from an approach around assessment of 'users' and separately for 'carers', to reflect a more person-centred approach for both those that need or give care. Guidance should be developed for practitioners to spread good practice that is geared around providing 'family support' – rather than provider-led, separate assessments. This would support practitioners in handling a conversation with people with care needs in a way that reflects those persons' choice and control, and, where it is identified that they have a carer providing regular, substantial care, to have a conversation with carers, too, about their support needs and choices. In practice, this may involve a social worker spending part of the session just with the user, part just with the carer, and part with the family as a whole.

The aim of this would be to facilitate better dialogue about needs and choices between both individuals and practitioners, and between support for those that need and give care. Government has recently acknowledged the need to 'think family' on issues of social exclusion, and has focused on families with children and with multiple and complex needs (Social Exclusion Task Force 2008). A family support process replacing current assessments for carers would expand this to consider families through the life course, including families that have adults with care or other complex needs.

We summarise our recommendations on assessment and budgets in Box 5.3 on the next page.

Box 5.3: Recommendations for the family

- **Support personal budgets:** Local authorities should offer personal budgets using resources from the reform grant already committed by the Department of Health (HM Government 2007). Restrictions on the use of budgets to employ family members living within the same household should be introduced. Practitioner and professional support should be available to users, including practitioners able to take a budget-holder lead professional role to support management of services for those who want that service. Professional support (or brokerage), and peer support and advocacy should continue to be available to all users (see also chapters 6 and 7).
- **A separate personal budget for carers:** This should be for those carers providing primary, intensive care roles, independent of carers' employment status. The budget could be used to purchase whatever support and services they need to enable them to care, including taking short breaks. The current eligibility for assessment – of giving 'regular and substantial care' – or a threshold of 35 hours a week (as with the current Carer's Allowance) could be used to establish eligibility. The budget could consolidate resources spent on carers from various funding streams, including the carer's grant, any direct payments to carers, respite care and potentially Income Support premiums on Carer's Allowance. (This proposal sits alongside proposals made in ippr's first paper on care [Moullin 2007] for all carers not in work to access a single benefit with the same rates and access to employment support as those out of work for other reasons.)
- **Family support:** In collaboration with the Association of Directors of Adult Social Services and the Social Care Institute for Excellence, and other relevant partners, the Department of Health should develop guidance on self-directed or person-centred assessment of adults with care needs, and on how to integrate this with an assessment of family needs, with the support of a key worker for a family.

6. Providing a whole service: integration and information

The success of the vision outlined in the previous chapter of promoting independence through personal budgets and assessment in families depends upon how much state support is available. But crucially it will also depend on the method of organisation and delivery in local communities of the range of services that support independence for adults with carer needs and their families.

Personal budgets will drive service improvement and integration from the users' end. But if they are to do this effectively, two other features must be present. First, the range of services will need to work together to personalise support to achieve these outcomes for individuals and their families. Second, services need to be accessed, shared and supported by the whole local community. This chapter and the next set out why and how these features of the service could be improved.

'It's higgledy-piggledy care'³

The long recognised and persisting divide between social care and other local services prevents services for both adult users and their families being sufficiently personal.

A range of policy changes have tried to address this issue, and the divide between health and social care services in particular. Table 6.1 on the next page summarises the main changes made at the levels of finance (how money is shared), governance (who is responsible for what), and strategy (how services are planned), and an assessment of each.

The inability to share resources and access points prevents these attempts at partnerships from fully integrating services around people's needs. Social care, a local and means-tested service, still sits in blunt contrast to health care, which is national and free at the point of use. This structural divide is far blunter than the grey area between people's health needs and their other care needs. As chapter 2 showed, users of social care services are also likely to be frequent and significant users of health services, either for themselves – it is known that carers too are more likely to have health problems – or on behalf of the person they care for.

'Continuing care', which is help with washing, dressing and eating for very ill and disabled people, illustrates the barrier over resources well. This type of care sits within the NHS – but is a type of care that would otherwise be provided on a means-tested basis by councils. Where such care is provided by the NHS, it can impact on the type and amount of social care services available. Despite a trend of moving away from institutional care settings towards more care in the community, the number of residential and nursing home places grew substantially in the 1980s as provision for continuing care in hospitals reduced (Netten *et al* 2005). The Department of Health introduced guidance and earmarked an extra £220m in October 2007 to ensure that eligibility criteria for the aspects of continuing care that are free at the point of need were fair and consistent. It was expected that this would lead to a 32 per cent increase in the number of people receiving continuing care, but in fact since then over a quarter of primary care trusts have reduced the number of people to whom they give NHS continuing care (Gainsbury 2008).

This case of what is called 'cost-shunting' between health and social care sits alongside evidence that cost sharing can reduce overall costs. Spending on social care particularly for older people can result in reduced costs for health services, by reducing the need for hospital admissions, and shortening hospital stays (Lundsgaard 2005).

To test a preventative approach among older people's services, 19 councils partnered with their NHS and third sector groups in 2006 to invest in services aimed to reduce hospital admission and length of hospital stay via the Partnerships for Older People Projects (POPPs). Early findings from the pilots show that, for every £1 spent on older people in the community, an average cost saving of £1 was achieved by reducing days older people spent in hospital (Macdonald 2008). The major obstacle was

3. This is a quote from one of ippr's focus group participants.

Table 6.1: Joining up health and care: recent policy change

	What?	How?	Success?
Finance	Health Act 1999, Section 31	Resources are allocated from health to social care through three flexibilities: pooled budgets, lead commissioning (where one body is able to delegate functions and transfer funding to the other to take responsibility and manage a single budget for commissioning both health and local authority services), and integrated provision.	400 partnership arrangements to date (involving more than £3.25bn of resource). Partnerships have improved efficiency, but successful implementation depends on high levels of local leadership
Governance	NHS Act 2001, section 75), Enabling Legislation	Merged senior management of Primary Care Trusts (PCTs), adult social services (and sometimes public health). 'Care Trusts' have joined up NHS and social care support for specific client groups, such as people with mental health issues in a separate organisation. In the unitary council of Herefordshire, a 'Super Authority', has been introduced (currently the sole example), which merges the PCT with the local authority. This involved appointing a single Chief Executive for both the PCT and the local authority (LA), and is aimed at creating a new legal entity in the form of a Public Services Board.	Competing priorities of NHS and local councils and differing lines of accountability remain. Few trusts developed; tend to be geared around narrow client groups. Remain limited as they do not provide for wider adult social care, or community health needs. Involve significant structural reorganisation. Merging PCTs and LAs is mired in legal complexity but efficient, reducing the costs of management and governance considerably. Thought to enhance local democratic accountability of health services.
Strategy	'Our Health, Our Care, Our Say' White Paper Local Government & Public Involvement Act 2007	PCTs and LAs have a duty to work together. Joint Strategic Needs Assessment (JSNA), between PCTs and LAs look at needs of local populations, and set direction of services to meet them. Joint Strategic Commissioning Local Area Agreements and Local Strategic Partnerships	Incremental improvement: discussing each other's commissioning does not always allow for shifts in priorities or towards services that prevent greater use of health and care services. Requires robust data on needs of the local area. No mandatory targets for adults in Local Area Agreements. Restricted by separate funding streams for health and care services.

Sources: IDeA 2008, Department of Health 2006, Health Services Management Centre 2003

moving funds from the hospital sector to sustain a shift towards providing care nearer people's homes. As the Local Government Association puts it: 'In areas where health and social care budgets stay completely separate, in the hands of the primary care trust and local council, there is no incentive for either partner to invest in actions that will save funding for the other' (Macdonald 2008: 66-67). Experience in other countries also supports this; see box 6.1.

Box 6.1: Integration of health and social care services in other countries

In some other countries, health and social care services are more integrated than they are in England. In Norway and Sweden, primary health care is fully integrated with social care at the local government level. New Zealand and Spain have integrated health and social care at a regional government level. These four countries' reforms share a number of features: the assessment of need from the perspective of different services (multi-disciplinary assessment); devolved budgets bringing together separate funding streams; either direct management of all relevant services or the power to commission them to regional or local government; and a single entry point for users and services and their families (OECD 2005).

Australia and Canada, while not structurally integrating primary health and social care, had a strong integration scheme, similar to the older people's pilots in England. However, evaluations show these two countries were more successful than the UK's current practice in achieving various outcomes due to two key features: involving the general practitioner in the assessment process, and providing a single point of entry to care services for users and their families (OECD 2005).

Inside and outside the system

A shrinking number of people needing social care services are given care funded by the local authority. The total number of hours of provided care has increased, yet statistics from the Commission for Social Care Inspection (CSCI) show that 100,000 fewer people received home care in 2006 than in 1997 (CSCI 2008). This suggests that while people who are receiving state-funded care receive more care, fewer people are state funded. If it is assumed people will not receive free care (from family or friends), it is estimated that 1.5 million people (60 per cent of the total number of disabled older people) would not be getting the care they need. However, when care received from family and friends is accounted for, only 450,000 people have a care shortfall, reminding us of the significance of unpaid caring (ibid).

Individual budgets have been seen to support equity by bridging 'the greatest inequity in social care [which] is the gap between those who can afford to self-fund their care and those who have to rely on poorly performing services' (Bartlett *et al* 2008: 48). People with savings and property worth more than £22,000 fall entirely outside the local authority system. Although everyone is eligible for an assessment of their needs, half of those who fund their own care do not receive care assessments (CSCI 2008). Evidence from the CSCI drawn from local authorities finds that people who have to self-fund their care often receive worse-quality services than those inside the system and lack information, professional advice and support. This weakens their ability to access quality services, make effective choices and so drive quality in the care market (CSCI 2008, Laing & Buisson 2006).

Carers ippr spoke to also found it difficult to access information and services: 'We have to fight; no one ever tells you what's out there, what you're entitled to.' Carers felt GPs in particular could do more to identify and support carers (OLR 2007).

The advantages and characteristics of a universal outcomes framework

This chapter has exposed two points of disjuncture that will hold back the degree to which services can be personal, high-quality and effective (including in cost terms): the disjuncture between health and care, and between people lying inside and outside of the social care system.

A universal outcomes framework for adults would address these in three ways. First, it would provide coherence to recent large structural and policy changes, under which to better evaluate these changes. Second, it could facilitate further integration at the local level between adult social care and other services supporting adults, including health. And third, it could smoothe the sharp divide

between those paying for their own care and those within the local authority system by rewarding local authorities that provide information, support and assessment to all and offering a basis against which eligibility criteria could be reviewed.

A shared responsibility

Outcomes for adults with care needs (and adults who are giving care) would be the shared responsibility of the local authority, not just the remit of adult social services. Adult social care may remain as a department and take a lead role, but the framework would enhance joint strategic commissioning arrangements by measuring performance jointly. Local councils could reflect this structure by having a lead member for health and care, or for adults, and a joint overview and scrutiny committee. Similarly, the Department of Health could reflect this framework by becoming explicitly a department for health *and care*.

Looking at outcomes across local authorities could also support central government in evaluating the development of various care trusts, which structurally integrate health and care for different groups, in some parts of England, against shared criteria.

Additionally, a shared framework for adults could also support the inspection and regulation of care services. The Care Quality Commission is to merge health and social care regulators – the Healthcare Commission with the Commission for Social Care Inspection (and the Mental Health Act Commission) – and hopes to integrate the inspection of health and care services. A clear statement of outcomes for adults could allay fears that under this new inspectorate best practice in social care around user-focus and rights-based approaches to services could be lost (CSCI 2008).

Responsibility for the whole population

Local authorities would be responsible for the outcomes for their whole population, not just those people they fund directly. Recently in the private market in care services both residential ('care homes') and non-residential ('home care') services capacity has decreased faster than demand (Laing & Buisson 2006). Local authorities would have a role in developing the local market for services with private and third sector partners, to ensure there is a choice of quality services.

New Local Strategic Partnerships (non-statutory, multi-agency partnerships that match local authority boundaries) offer a way to agree plans over how to achieve these outcomes. To ensure basic minimums against these outcomes are met across local authorities, these plans should be agreed with the Department for Health as part of Local Area Agreements. A universal outcomes framework should bring together and review existing National Service Frameworks (NSFs) for older people, people with dementia and various types of disabilities. The Audit Commission should then assess adult services as a core part of local authority assessments as part of their Comprehensive Area Assessments for local authorities.

Service quality across the private, third and statutory sectors is affected significantly by the nature of the workforce. The outcomes for people with care needs and their families, even under a system driven by individual budgets, depends on the professional people supporting them, and the paid care workforce, and therefore on how they are developed, supported and managed. (It is not within the scope of this paper to give these issues full attention.)

Information for all

Using the model of children's information centres, local authorities should provide universal information and support on care services, for all adults with care needs and their families, including those who fund their own care and those receiving local authority funded care. Information should be provided on the full range of service needs facing people with care needs and carers. Local areas should develop this in ways most appropriate to local need and existing services. Possible methods and channels for implementation and commissioning include:

- A **first stop shop**, that brings together and develops Centres for Independent Living (grassroots organisations run and controlled by disabled people), older people's information services, carers' forums and centres, and even ultimately the Pensions, Disability and Carers Service, currently a part of the Department for Work and Pensions.

- A **connected care centre** that houses multi-professional teams and signposts other services, to include social workers specialising in a range of client groups, 'brokers' between services, care workers and practitioners, and other information and advice (Rankin and Regan 2004).
- **Building on existing Children's Information Services** to create inter-generational family resource centres. An evaluation of Children's Information Services in 2002 by PricewaterhouseCoopers found that while the proportion of parents who used the service was small, satisfaction among users and providers was high (PwC 2002).
- **Building on community and primary health services**, such as GP practices and polyclinics (OLR 2008). A first step for more integrated service would be for primary health services to take a bigger role, as often these are the most visible, known and already used by people with care needs and carers in a community. The Quality and Outcomes Framework (QOF) for GPs should reward those practices that identify people that care for family and friends who are older or disabled, signposting them to other relevant services, and providing services such as home visits/out-of-hours.
- Building on and cohering existing good practice in the **third sector and through user-led organisations**. The third sector is especially well-placed to deliver information and advice, and involve users and volunteers (Audit Commission 2007, Neuberger 2008). The Government has already committed to having a fully functioning user-led organisation (ULO) in every local area by 2010 (PMSU 2005). ULOs are organisations that support independent living for disabled people, to give disabled people a chance to have their voice heard as well as supporting their choices, and have at least three-quarters of their management made up of users or potential users. They are valuable for their provision of advocacy on disabled people's behalf and peer support to users, in addition to advice over using services or personal budgets (Morris 2006). The Essex Coalition for Disabled People, for example, is looking to provide mentoring and peer support as well as brokerage advice over personal budgets and direct payments (Ivory 2008). Peer support for carers could also be extended by the expansion of the 'Expert Carers Programme'. This programme offers some carers peer support and training to help them in their caring role.
- A service housing **key workers or 'lead professionals'** that work with families. In Australia, 'Local Area Coordinators' – or key workers – work within a local community, usually from a shop premises. These coordinators hold small amounts of discretionary funding to give support to people directly, and they advise people about other services. People can walk in off the street to get help and advice on care services, as well as on education, training, community groups, volunteering and so on (Hatton *et al* 2008).

A useful policy comparison here is with childcare services. In this case, rather than having local authorities provide more, or fund all, childcare places themselves, a performance framework makes clear their role in developing information and advice services and the market for childcare services for all families in an area (DCSF 2006).

'Assess me once'

Assessment, both to enter the system and for those within it, is very burdensome for adults with care needs and their families. This is partly because people with care needs, and those caring for them, tend to use a range of local services – including health, housing, and welfare support as well as social care. As an ippr focus group participant put it: 'Every time you have an assessment you start all over again.'

The Department for Work and Pensions (DWP) has developed a 'Tell Me Once' scheme for recording changes in circumstances affecting people's tax and benefits (Varney 2006), and we propose that an 'Assess Me Once' scheme along similar lines is developed for adult services. As people with care needs and their families tend to regularly use multiple services more than other groups, the development of information sharing to simplify and reduce assessment and administration should be prioritised for this group. The involvement of national agencies, the NHS and DWP in particular, would extend the 'Tell Me Once' scheme and further help to offer simpler access to, and more efficient assessment for,

services (IDeA 2007). However, risks to both data protection and data security would have to be considered and assured in any scheme. An 'Assess Me Once' scheme could support a common approach to assessment of need across DWP and adult social care services, and even some aspects of health and supported housing services.

As well as reducing the burden and cost of duplicated and inconsistent assessment, such a scheme could also serve as a platform for integrating multiple funding streams into individual budgets. While a 'common assessment framework' for adults' health and social care needs has been piloted to promote self-assessment and reduce duplication of assessment following the white paper 'Our Health, Our Care, Our Say' (Department of Health 2006), current plans for primary and community health services give little impetus to do this (OLR 2008).

Pooled budgets

The integration of services and support for adults with care needs could be further facilitated through flexible funding streams for personal budgets. One of the advantages offered by the personal budgets over direct payments and local authority commissioned services has been that they allow multiple funding streams to go into one simple, shared pot. Individual budgets, currently piloted by the Department for Health, differ from personal budgets by drawing on five different funding streams. This is a critical way in which individual budgets differ from, and advance on, direct payments and personal budgets which are made up from adult social care funds, and the separate 'Independent Living Fund'. A further advance would be to make it possible for resources for budgets to be drawn from the NHS, in addition to other streams, in circumstances that may prevent hospital (re-) admission, or in 'continuing care' situations, when people are discharged from hospital stays.

Further alignment between health and care resources could be facilitated through the introduction of individual budgets, using multiple funding streams, at the boundary between health and social care. This would affect individuals whose needs currently blur between health and social care service divides: people with mental health care needs and some long-term conditions, such as those that affect mobility. As some services for these groups of people are funded centrally and are universally free at the point of use, offering support via a cash budget could be difficult. However, an individual budget would let recipients know the full amount of resources available to spend on them, and involve them centrally in a discussion of how to spend those resources in a way that best meets their needs. In the case of mental health, where services may be provided to adults under compulsion, we would expect the use of key workers managing individual budgets to be more prevalent.

Eligible older people, disabled people and carers currently receive some cost support that is separate from income replacement benefits and pension, based on the intensity with which they need or provide care. This comes in the form of Disability Living Allowance (DLA), Attendance Allowance (AA) and Income Support premiums on Carer's Allowance (CA). The introduction of individual budgets, by providing support in the form of cash and not just services, could potentially also offer an opportunity to bring together in one place financial support for the additional costs that face adults with care needs and their carers, costs that are currently provided by different parts of the welfare and care system.

However, the potential benefits of bringing together this financial support in one place depend on what changes are made to how social care is financed in the forthcoming green paper. If a high level of local variation in social care funding support remains, and if it continues to be restrictively means- as well as needs- tested, shifting cost support from welfare to the social care system is likely to result in a large number of people losing out (Berthoud and Hancock 2008). However, if we were to see more people eligible and entitled and a wider group funded by local authorities, it would be efficient and simpler to move DLA, AA and the premiums on CA into the social care system through individual budgets and carers' budgets. This could also significantly reduce the amount of necessary assessment, to involve a single assessment for accessing a whole package of support, as proposed above.

Box 6.2: Recommendations 3: The service as a whole

- **Outcomes:** A national outcomes framework for adults should help bridge the divide between health and care and between those within and outside the state system. Local authorities would be assessed as a whole on how they improve outcomes for adults, supporting greater integration of services. Local authorities could also be assessed against outcomes for their whole population, not just those they fund directly. Against this framework, government could better evaluate ways in which governance is integrated, such as through Care Trusts. A successful framework covering the whole population would also incentivise the provision of information, advice and the development of the market with private and third sector partners.
- **Information:** Outcomes for people with care needs and caring in the whole population should be a council-wide concern, not just the remit of adult social services. To this end, local authorities should commission services to provide information and advice on care, in a way that suits local people's needs, preferences and existing services.
- **Assessment:** Authorities should develop an 'Assess Me Once' scheme, to integrate multiple assessments in adult social care, health, and even housing and welfare services.
- **Resources:** The NHS should be able to provide resources for personal budgets for adults with care needs, where care support may prevent hospital (re-) admission, or in 'continuing care' situations, as people are discharged from hospital stays. Personal budgets could be introduced on the boundary between health and social care services, for people with mental health care needs and some long-term conditions, such as those that affect mobility. In these cases, where there is a universal entitlement to services, or where services may be provided under compulsion, we would expect greater use of key workers to hold and manage individual budgets, but users could still be involved in discussion of choosing services.

7. Making community voice heard and encouraging volunteering

The language of 'care in the community' has dominated social care over the last 20 years. The practice of 'care in the community' aimed to move people out of institutional (residential) care homes and into the community. Far more people are now cared for in their own homes, with improved outcomes as a result. However, evidence suggests that in practice this has meant an increase in the number of people who are providing intensive levels of care unpaid (CSCI 2008). At the same time, communities have remained under-involved in caring, meaning people with care needs and those that provide care in families are often still isolated. Social care is still thought of as serving a marginal group of people, rather being something that local communities should be engaged in, supported and held accountable (Kendall and Harker 2002).

As a society, it is argued, we have to assume a reciprocal responsibility for people with care needs and people caring in order for all concerned to live independent or equal lives. This idea of a public 'ethic of care' has been seen to be critical to a view of justice that extends to those that give and those that receive care (Kittay 2000). Studies in the United States have seen such support over care as a civic virtue, and as a form of social capital (Bellah 1994). Caring is more than the direct exchange of a good: some see it as part of an 'economy of regard', where care is given as a gift to others. Care support is a generalised form of giving and receiving that recognises care as a public activity, as well as private value, which can strengthen and sustain communities (Fine 2006).

The need for voices to be heard

Public engagement is particularly important in those care services in which some of the desired outcomes – enhancement of dignity, choice and control – are best evaluated by individual users themselves, and where disabled or older users and carers have often felt excluded and powerless in relation to services. As one of ippr's focus group participants put it: 'You're invisible. No one listens to what we want.' Moreover, better community engagement in care services could go some way in countering the difficulties arising from the fact that as care services are not universally used, are often poorly understood and lack identifiable institutions or professionals, they command less status and support among the public than do hospitals and doctors, schools and teachers (Kendall and Harker 2002).

While personal budgets give choice and control over one's own services, there is also an important role for users, their families and wider communities to participate collectively in care services, to shape them and hold them to account. Indeed, strengthening spaces and routes for local communities, adults and their families to collectively shape their services would prevent an approach that makes greater use of personal budgets from undermining collective institutions.

Experts by experience

The Commission for Social Care Inspection (CSCI) has piloted an 'experts by experience' programme for users of care services to be trained and supported in inspecting and assessing care services. Evidence from the pilot and disabled people's groups' response to it suggest it has been a successful approach to building in a user-led perspective on quality to regulation. To ensure this is not only retained but strengthened under the new Care Quality Commission, the Department of Health should set a target for the inspectorate to conduct 50 per cent of its inspections of care services involving an 'expert by experience'. Users and carers should be offered appropriate training in inspection and expenses to enable them to undertake an inspecting role.

An Expert Carers Programme has offered similar peer training, support and advocacy to carers, to help them both in their caring role, and in navigating and advocating for the people they care for, and in care services. The Department of Health should aim for an Expert Carers Programme to be available in every local community – either through the Primary Care Trust or local authority. The services could potentially be commissioned from current third sector carers' groups, or work alongside user-led organisations for older and disabled people.

Local Involvement Networks

Local Involvement Networks started in April 2008, replacing Public and Patient Involvement Forums, and aim to coordinate the range of third sector, public, user and carer involvement across health, care and other services. There are a number of ways in which their role could be strengthened to improve community accountability for services. For example, the Care Quality Commission could have a statutory duty to consult with Local Involvement Networks (LinKs). Similarly, Local Councils' Overview and Scrutiny Committees on health and care services could have a duty to consult with LinKs and there should be a lead member for adult health and care. The Care Quality Commission should also have a role in assessing LinKs to ensure they are effectively representing both people with care needs and carers. This would include working with user-led organisations, and making necessary provisions for people with care needs or carers to be involved.

Volunteering

Census data suggests that 21 per cent of all people caring for at least one hour a week are caring for friends or neighbours, rather than family members (ONS 2001). The term 'unpaid carer' usually refers exclusively to people carrying out an intense primary caring role rather than to volunteers. Yet, informal care-giving could be extended in the form of volunteering, which has been defined recently as 'an activity that involves spending time, unpaid, doing something that aims to benefit the environment or individuals or groups other than (or in addition to) close relatives' (Neuberger 2008). This would help extend people's networks and relationships; as one older carer said of her adult daughter who has learning disabilities: 'It's not good for her to just have me; she needs to make other relationships.'

By encouraging voluntary support for care, it might be possible to shift the notion that care is something carried out by hidden-away carers working at high intensity for 'dependent' care recipients, and towards a more reciprocal, interdependent relationship across communities and generations. Evidence suggests that while highly intensive caring often has a negative effect on health, social inclusion and economic outcomes for the carer, caring at lower intensities can have the reverse effect (see box 2.1 in chapter 2; and Lloyd 1999). Participants in our focus groups felt that as much as their intensive caring roles were valued, the opportunity to have relationships outside the caring relationship was also important to them.

Rather than looking just at the 'supply' of intensive carers, we should look to how the duty of care could be better shared, to support both adults with care needs and their families. Wider community support and engagement over caring could support current groups caring to remain so, and enable others to provide some unpaid care. Volunteering generally is something undertaken by a significant proportion of the population: according to one study nearly 40 per cent of people had been formal volunteers in the year prior to being interviewed, and a further 20 per cent said they volunteered regularly (Cabinet Office 2007).

Pressures on respite services for disabled, older people and those caring for them, and expected rising demand for 'informal' forms of caring support, suggest that using volunteers for caring roles is an option that could be developed further. Indeed, some of the advantages of volunteering that have been identified are particularly relevant to care: promoting equalities and supporting services to be more user-led, as well as, critically, 'making services personal and genuinely caring' (The Commission on the Future of Volunteering 2008).

A recent review for government has shown that volunteers are both under-utilised and under-supported in health and social care services (Neuberger 2008). Volunteering cannot substitute formal, professional support for care services and for unpaid carers in families; however, volunteering could play a role in supporting a mainstream, collective experience of giving care. Box 7.1 shows the experience of one scheme in Japan.

Box 7.1. Using volunteers to support care in Japan

In Japan there has been a successful scheme that offers community credits for caring for older people. Those who volunteer gain non-monetary credits for both the time they give and the nature of the help they provide (personal care earns more credits than help with shopping, for example). These credits can be exchanged for in-kind services, transferred to other people such as relatives, or even used as credit for one's own future caring needs. In some areas, credits can also be used to access local authority services and facilities.

The quality of care given through the scheme has been found to be of higher quality than that of paid-for care. Moreover, it is preferred by the people receiving the care themselves, as it is not regarded as simply charity. The scheme can also provide advocates for people with care needs and support for carers.

Source: Aldridge *et al* 2002

'Care share' schemes

To support and expand a pool of 'informal' carers, we propose that local authorities consider developing a 'care share' volunteering scheme, to include making use of online time-bank systems, working with existing third sector organisations and user-led organisations in a local area. An accompanying public information campaign could also encourage a wider range of people to support older and disabled people and their carers. This would not just be in terms of actual care provision, but also in terms of advocacy and wider engagement. The scheme development could be led by disabled and older people themselves, to ensure it is designed in a way that best supports advocacy for, inclusion and participation of people with care needs in a non-patronising way. As it would involve working with those called 'vulnerable adults' in legal terms, the scheme would require Criminal Records Bureau checks, and training and support as appropriate.

In order to be consistent with giving people with care needs choice and control over by whom and how they are cared for, the scheme could be regulated by the Care Quality Commission to ensure that it meets these outcomes, including protecting the recipients' human rights. This is particularly important for people with learning disabilities.

Local authorities could adapt or develop the scheme in different ways. One idea would be to have an intergenerational focus, with young people encouraged to help care for older and disabled people, by relating it to the 'V' volunteering programme for young people. Another would be to remove barriers for disabled and older people (including service users) themselves to volunteer. Some of the Government's recent commitment to invest £2 million in an access to volunteering fund for disabled people (Cabinet Office 2008) could help facilitate further support over care in particular. The 'younger-old', including newly retired people, are often active volunteers and have higher rates of participation in volunteering than people aged 75 and over. The 75 and over age group has the lowest rate of volunteering of all kinds. Supporting this group into volunteering could help them to be more active and included in old age, as well as acting to provide more care.

A care share scheme could play one part in helping to retain and mainstream the value of care as a responsibility and duty, while acknowledging the costs in terms of independence and inclusion faced by both those giving and receiving care.

Box 7.2. Recommendations 4: The whole community

- **'Voice':** Public engagement and accountability, and therefore also service quality, could be enhanced through the extension of inspections of care services that involve 'experts by experience' in the Care Quality Commission. The Department of Health could set a target for the inspectorate to conduct 50 per cent of its inspections of care services with at least one 'expert by experience'. Users and carers should be offered appropriate training in inspection and expenses to enable them to undertake an inspecting role. Additionally, the Care Quality Commission should have a duty to consult with Local Involvement Networks (LinKs).
- **Volunteering:** Local authorities should consider better utilising and supporting volunteer support for care through a 'care share' volunteering scheme, where adults with care needs could choose appropriate care, support and advocacy from volunteers. Volunteers, including disabled people and carers as peers, could gain reciprocal support through a credit exchange.

8. A whole-system view of costs

The costs of care need to be considered within the context of the whole economy, taking on board the cost of unpaid care, formal care services, and the cost to health and welfare as well as social care services. There are direct costs borne by services, and costs associated with individuals being prevented from fully participating in society and the economy.

The cost to the economy of those who are caring for more than 20 hours a week and who are unable to take on paid employment is £5.57 billion. This is more than two-thirds (63 per cent) of the £8.73 billion cost of replacing that care fully with formal services (see Moullin 2007). The proportion is similar for those taking early retirement and who are otherwise not in paid employment due to caring. These figures only take into account the loss of annual potential earnings, not the cumulative or wider costs in terms of health and housing services for carers. Given that formal care services do not substitute directly for care provided 'informally' or unpaid, and that there are wider and cumulative costs of not supporting carers (Pickard 2007a), we can present a sound case for increased investment in formal care services.

Social care services also contribute to the efficiency of the acute health care sector. This happens by reducing the numbers needing care in the sector and shortening the length of stay through support following patients' discharge. A national inquiry found that 20 per cent of hospital bed days for people over 65 would be unnecessary if alternative care services were available (Fernandez and Forder 2002, Netten *et al* 2005). Early evidence from the Partnerships for Older People Project pilots, in which councils and their NHS partners have jointly developed systems of care for older people, shows that, on average, for every £1 spent on older people in the community, £1 is saved by reducing the number of days older people spend in hospital.

Finally, care services that enhance the participation of older and disabled people, in the economy if not the labour market, can also enhance productivity. Evidence suggests that we can expect an increase in individual productivity as an output of any service, including social care, that aims to improve people's 'health, functional capacity and prevention of deterioration' (Malley and Netten 2007). Even if we exclude the costs of health care from Dame Carol Black's recent review into the health of the working age population, which includes mental health and mobility problems, the cost to government is estimated to be £58-65 billion and the cost to the economy as a whole £98-118 billion (Black 2008). While there is little good-quality data calculating the potential productivity loss of disabled people denied employment opportunities partly as a result of their receiving inadequate care, government recognises that these costs would be substantial (PMSU 2005).

This paper has argued that care services should be conceived of as an integral, central part of an active welfare system, supporting individuals, families and communities to participate in society, as well as in services. This has implications for questions about spending on social care services, moving away from one of the costs of sustaining a group of 'dependent' people and towards one of what price society puts on the equal participation and citizenship of adults with care needs, and those that care for them. Promoting independence for older and disabled people is not just the fairest approach to care; it is the most cost-effective approach to adult services.

9. Conclusion

To date care has been only peripheral to our understanding of social justice and public services. Compared with schools and hospitals, care has lacked the service identity and policy priority that would give it the public attention and political urgency it requires. This must change. People's ability to live independent, equal and dignified lives pivots on care, and therefore care should be at the core of a just society.

We must start from individuals' rights to independence. But we must recognise that it is care and services that sustain the families and communities in which rights can be articulated and independence achieved. A lack of care, for example, can be as disabling as not being able to choose or control the care a person does have.

Considering care in this way enriches our concept of social justice, and of the state. By doing this, it also offers lessons for how we could design and deliver public services more widely. It is by turning attention to services for people who are disabled that we actually see how a society that enabled people to live active and flourishing lives would look, and to develop a strong, progressive vision of how to reform public services more widely. Focusing on individuals, their outcomes and choices is not to say that we should dispense with families or allow the state to be neglectful. It does, however, give us reason to rethink families' roles and redesign services.

The state model that sees empowering individuals and promoting care in families and communities as opposite objectives needs to be discarded. 'Family policy', in which we think about how the state supports care and families, needs to run right through public policy. And any public service 'transformation' needs to consider how the range of services works for individuals within a community. Placing a spotlight on how we promote individuals' independence quickly highlights how interdependent we all are. Empowered individuals, caring families and communities and strong public services all need one another.

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Appendix A: Methodology

1. Case studies

ippr shadowed four unpaid carers for one day each in order to better understand carers' own experiences and to add their voice to our research.

The shadowing comprised a researcher spending a large part of a day with a carer, the person that they were caring for and any co-carers, family and formal carers present. The shadowing was conducted in the form of 'participant observation': rather than simply observing the carer, the researchers interacted with and involved themselves in the carers' lives where possible and appropriate. In some cases this involved helping the carers with chores around the house, in others accompanying the carers on activities outside of the house. In all cases the researcher conversed with the carers throughout the day and asked them questions where appropriate.

ippr felt it was important that this research was reflexive and took account of the individual circumstances of each set of carers and the people they cared for. Therefore although there were some set background questions asked of all carers to enable the researcher to draw comparisons, there was no focused discussion guide.

In each case, the shadowing was followed up by a semi-structured telephone interview, which again was not prescriptive.

Benefits of using this methodology

Adopting this shadowing approach gave our researchers an insight into the carers' lives that could never have been acquired through interviewing alone. Rather than simply listening to the carers' stories, researchers were able, to a small extent, to experience them themselves. Shadowing can be a difficult methodology since the presence of a researcher may compromise the participants' behaviour. In this case, however, it was felt that the carers could only adjust their behaviour to a small degree given they had caring duties to carry out and the informal approach taken by the researchers encouraged the participants to continue with their normal routine.

The follow-up interview was conducted within two weeks of the shadowing, enabling the participant time to digest the researcher's presence and add anything they felt was important to their story or ask questions about the research. It also enabled the researcher to fill in gaps in the information that they had collected.

Recruitment of carers to the study

The carers were recruited through local carers charities. In each case the carers were contacted by the charity in the first instance and given information about the project and what the shadowing would entail. Where the carers gave permission, their contact details were passed on to an ippr researcher. The researcher then contacted the carer by phone to explain the project in more detail. If the carer was happy to go ahead then a date for shadowing was arranged. It was emphasised to the carer that they could change their mind and withdraw from the research at any stage.

Write-up of case studies

The shadowing was written up by the researcher who had undertaken the shadowing as soon as possible after the shadowing was completed. The write-up was then adjusted following the telephone interview. In each case, the carers were sent a copy of the write-up to ensure factual accuracy and that they were happy with the way that the researcher had portrayed their story. It was emphasised to the carers that the write-ups comprised the researchers' own understanding of the carer's story.

Ethical considerations

This research demanded clear ethical guidelines. These were:

- All potential participants were contacted by a carers charity in the first instance, not directly by ippr.

- All participants were given full details of the project and what the shadowing would involve.
- All participants had to give their permission for the research to go ahead and had to seek the permission of the person they were caring for and co-carers/family members where appropriate.
- It was emphasised to all carers that they could cancel the research at any time.
- The timings of the shadowing were set by the carers, not the researchers.
- The researchers made sure that the carers had their contact details at all times.
- All carers were given the opportunity to read and edit their write-ups at least once.
- None of the write-ups included participants' personal details.
- Carers were not given an incentive for taking part in the research but were thanked afterwards with a gift chosen by the researcher.
- The two researchers working on the project both had full Criminal Records Bureau clearance.
- After each shadowing day, the researcher involved had a full debrief with a suitable ippr staff member to ensure that any emotional responses to the shadowing did not adversely affect either the researcher or their write-up.

2. Focus groups

In addition to the in-depth case studies, two focus groups were conducted with a mix of carers. No criteria related to age, social grade or gender were set during the recruitment process. All respondents were contacted and recruited through Carers Forums in Islington and Hackney, London. The findings from this research must be viewed in the light of this method of recruitment as carers who do not currently attend a Carers Forum in these areas were not invited to take part.

The very nature of such research means that only a small number of carers were involved in the discussions. The total sample is too small to allow for robust statistical analysis. This qualitative research does, however, enable us to glimpse carers' views and opinions and sits in addition to the in-depth qualitative work and secondary data analysis.

The focus groups were conducted on 6 February 2008 in Islington and 27 February 2008 in Hackney. Both focus groups were moderated by an experienced research consultant and were conducted on-site at the Carers Forum's headquarters. Each group lasted approximately 90 minutes.