interlinks

Health systems and long-term care for older people in Europe
Modelling the interfaces and links between
prevention, rehabilitation, quality of services and informal care

Governance and finance in long-term care

National Report England

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SEVENTH FRAMEWORK PROGRAMME

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Table of contents

1 Introduction and background

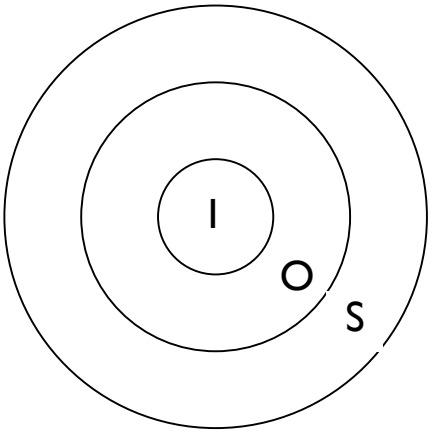
Building on learning from work packages (WPs) 3-5, this element of INTERLINKS focuses on the governance and financing of long-term care systems. Taking place primarily in year 2 of the project, WP 6 has to strike a balance between:

- Learning from WPs 3-5 so as to understand more about how to incentivise and embed good practice in everyday practice.
- Providing contextual analysis to help make sense of what is possible in practice in different national systems.

In this way, WP 6 will need to work both bottom-up and top-down at the same time, and close liaison will be needed with the SMT and WPs 3-5.

To illustrate this issue, Glasby (2003) has previously argued that governments seeking to promote more effective inter-agency working need to focus on three separate but inter-related levels (see Figure 1). Thus, the contribution of individual practitioners (I), though significant, takes place within a local organisational context (O), which itself is influenced by structural barriers (S) to improved joint working. Similarly, structural barriers derive at least in part from certain organisational features associated with particular types of health and social care agency and, ultimately, from the individual practitioners working within the organisations concerned.

Figure 1 Understanding inter-agency working



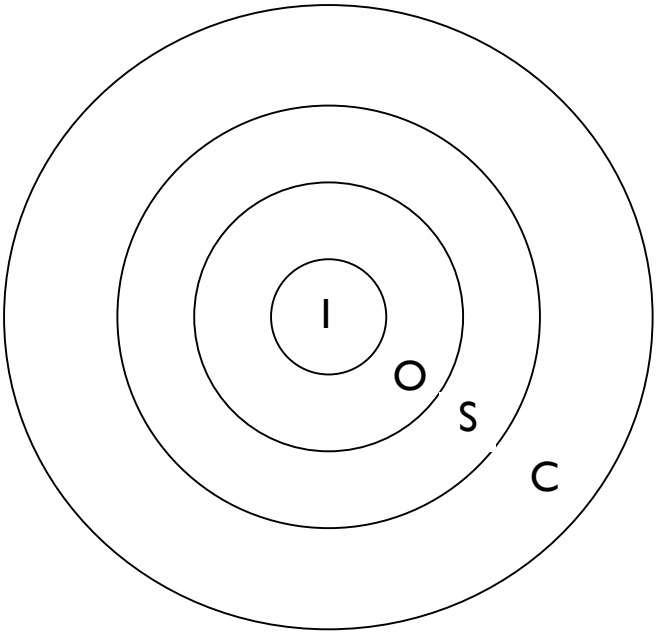
I: the Individual level

O: the Organisational level

S: the Structural/System/Social Policy level

In translating this model from a national to an international context, a forth level of analysis is probably required – that of context and culture (C) – see Figure 2.

Figure 2 Understanding inter-agency working in an international context



I: the Individual level

O: the Organisational level

S: the Structural/System/Social Policy level

C: the Contextual/Cultural level

Building on this approach, WP 6 focuses on the structural (S) and contextual (C) factors that influence (and are influenced by) individual (I) and organisational (O) practice at more local level. In particular, the aim of WP 6 is to explore:

- The contextual (historical, political, cultural etc) factors that influence the provision of long-term care.
- The way in which long-term care services can be governed and financed in order to incentivise and embed good practice in everyday practice.
- Issues of financial sustainability.

1.1 Key definitions and frameworks

All too often, many debates about 'governance' tend to use this concept in a way that makes it indistinguishable from the concept of 'management'. While there is a broad literature on this issue, a potentially helpful definition is provided by Hodges *et al* (1996, p.7), who see the term 'governance' as relating to:

> *"The procedures associated with the decision-making, performance and control of organisations, with providing structures to give overall direction to the organisation and to satisfy reasonable expectations of accountability to those outside it."*

This seems particularly useful given the emphasis at the end of the definition on accountability to those 'outside' the individual organisation – which might be a helpful starting point given the whole systems focus of INTERLINKS. When seeking to examine the inter-action of different health and social care services, Hudson *et al* (1997) have identified a series of barriers and success factors when seeking to develop a whole systems approach (see Figure 3).

Figure 3 Hudson et al's summary of key barriers/success factors

Barriers to inter-agency collaboration include:

- **Structural** (fragmentation of service responsibilities across agency boundaries, within and between sectors).
- **Procedural** (differences in planning horizons and cycles; differences in budgetary cycles and procedures; differences in information systems and protocols regarding confidentiality and access).
- **Financial** (differences in funding mechanisms and bases; differences in the stocks and flows of financial resources).
- **Professional** (professional self-interest and autonomy and inter-professional competition for domains; competitive ideologies and values; threats to job security; conflicting views about clients/consumers' interests and roles).
- **Status and legitimacy** (organisational self-interest and autonomy and inter-organisational competition for domains; differences in legitimacy between elected and appointed agencies).

Principles for strengthening strategic approaches to collaboration include:

- **Shared vision** (specifying what is to be achieved in terms of user-centred goals; clarifying the purpose of collaboration as a mechanism for achieving such goals; and mobilising commitment around goals, outcomes and mechanisms).
- **Clarity of roles and responsibilities** (specifying and agreeing 'who does what', and designing organisational arrangements by which roles and responsibilities are to be fulfilled).
- **Appropriate incentives and rewards** (promoting organisational behaviour consistent with agreed goals/responsibilities, harnessing organisational self-interest to collective goals).
- **Accountability for joint working** (monitoring achievements in relation to the stated vision; holding individuals and agencies to account for the fulfilment of pre-determined roles and responsibilities; and providing feedback and review of vision, responsibilities, incentives and their inter-relationship).

Drawing on this framework, the remainder of this paper reviews the governance and financing of English long-term care for older people.

2 Key contextual factors

In England, many current welfare services were initially established following the Second World War with a particular focus on providing a basic safety net for those in severe need. Building on this legacy, UK health and social care have historically tended to have something of a crisis focus, targeting resources on those in greatest need. Because of this, many current approaches have developed from an institutional background, with the main focus of the system on large, resource-intensive services such as hospitals and care homes. While a series of more community-based services began to develop from the 1960s onwards, the emphasis has still primarily been on meeting the needs of people in crisis. Further details of more recent attempts to address this are set out in a previous report for WP 3 (rehabilitation and prevention). Summarising a complex history, the governance and financing of services for older people in England are influenced by three main factors:

- Since the creation of the British welfare state in the late 1940s, there has been a strong commitment to the principle of a publicly funded National Health Service (NHS), available on the basis of need and free at the point of delivery. This remains a central feature of British society, and all major governments have continued to support this concept (often competing to portray themselves as a champion of the values which the NHS embodies). For historical reasons, adult social care is subject to a means-test, and older people often have to contribute financially towards the cost of their care.
- Adult social care emerged out of the poor law and the workhouse of the nineteenth century, so remains more of a targeted and (to some extent) stigmatised service than the NHS. For historical reasons, adult social care is subject to a means-test, and older people often have to contribute financially towards the cost of their care. It is to rectify some of these historical influences that a current Adult Social Care Green Paper is debating the future principles and funding of adult social care and care home provision (HM Government, 2009).
- From the early 1980s, English health and social care have increasingly adopted market-based approaches to reform, with a growing emphasis on choice and competition as a means of improving standards and value for money. Thus, while there remains a strong commitment to publicly funded, comprehensive and universal services in many areas of the welfare state, such support is often provided in practice by a much more mixed economy of public, private and voluntary sector providers.

3 The governance and financing of long-term care services for older people

For historical reasons, the English welfare state has tended to assume that it is possible (and meaningful) to distinguish between people who are *sick* (who are seen as having *health care* needs, met by the NHS free at the point of delivery) and people who are merely *frail or disabled* (who are seen as having *social care* needs that fall under the remit of local authority social services and that are frequently subject to a means test and user charges). Despite substantial policy changes, this 1940s' distinction remains largely intact (see Means and Smith, 1998; Glasby and Littlechild, 2004; Glasby, 2008 for an overview). Arising out of this, contemporary health and social services have to overcome a series of barriers – organisational, financial, legal, professional and cultural – if they wish to work together more effectively (see Table 1 for a summary of the key differences between health and social care).

Table 1 The health and social care divide

	Health Care	Social Care
Accountability	National (to Secretary of State)	Local (to elected councillors)
Policy	Overseen by Department of Health (which also has responsibility for social care policy)	Local government is overseen by the Department for Communities and Local Government – although social care policy is the responsibility of the DH
Charges	Free at the point of delivery	Means-tested and subject to charging
Boundaries	Based on GP registration	Based on geography and council boundaries
Focus	Individual (medical) cure	Individual in his/her wider context
Culture/training	Strongly influenced by medicine/science	Strongly influenced by social sciences

Source: Glasby, 2008.

Currently, older people's services are commissioned by local authority adult social services and by Primary Care Trusts (PCTs). The latter are local NHS bodies tasked with commissioning acute care (from a range of local/regional acute hospital trusts), mental health care (from large mental health trusts), community health services (from an increasingly mixed economy of providers) and primary care (from local general practitioners). In the past, PCTs both commissioned and provided services. More recently, their role has focused primarily on commissioning (and many have either divested themselves of their provider services or developed a clear organisational separation between their commissioning and providing functions). Over significant time, both local authorities and PCTs have been increasingly working together to commission joint services from a range of public, private and voluntary providers.

Increasingly, health and adult social care are being asked to work in a more collaborative (and sometimes a more integrated) manner, carrying out a joint annual assessment of the needs of the local population, developing more senior joint posts, pooling some health and social care budgets, carrying out a

single assessment of need and developing some joint teams of social workers, district nurses and other professionals working in the community with older people. There is also a strong emphasis on developing more joint community alternatives to traditional institutional forms of care (such as care homes or hospitals). Individual care is often co-ordinated locally (to an extent) by a care/case manager and/or by an agreed lead professional. Whereas most health care is freely available to all in an emergency or available via GP referral for planned care, adult social care is subject to increasingly stringent means-testing and eligibility criteria. Historically seen as passive recipients of state care, service users are now increasingly being recast as 'consumers' or even as 'citizens' (with greater rights but also responsibilities). There is also a strong emphasis on supporting people with long-term conditions by promoting greater self-care. Families, friends or neighbours who choose to provide care for older people have a legal right to an assessment of their needs and can receive a number of support services (either provided to the person they care for or in their own right). The English welfare state has aimed to provide equal support to people in equal need – albeit that services have often been inadvertently designed with a white, male, middle class norm in mind.

More recently, the English government has pledged to roll out a national system of personal budgets throughout all adult social care, and is also piloting personal health budgets. While this is explored in much more detail elsewhere (Glasby and Littlechild, 2009), the development of more individualised funding has the potential to challenge traditional organisational hierarchies and professional power by putting individual service users more in control of their support and hence their lives. In particular, this has been described as moving away from a system based on the notion of a 'professional gift' to one based on active 'citizenship' and as a fundamental shift in the nature of the relationships between the state and the individual.

4 Key barriers to joint working

4.1 Structural

As suggested above, services for older people in England are fragmented between different health and social care systems, each with different legal and financial frameworks, geographical boundaries, accountability mechanisms and cultures. However, within health care itself, responsibilities for different parts of an older person's care pathway may be split between general practitioners (often private practitioners working on behalf of the state), community health services (provided by the PCT, by a community trust or a social enterprise), specialist mental health services (provided by a mental health trust) and acute care (provided by a hospital trust). Adult social care also tends to have separate teams for older people and for people of working age, so there can be additional structural barriers here. Broader services which might also play a role in supporting older people (for example, housing, transport, leisure etc) are typically overseen by other local authority departments. For all that the health and social care divide can be so problematic, a major irony is that health and social care often have more in common than social care does with its other local authority colleagues – sometimes even in areas where adult social care is co-located in the same directorate as other services (such as housing).

4.2 Procedural

Arising out of separate organisational structures and legal frameworks, different health and social care agencies have different policies and procedures, including approaches to terms and conditions, pensions etc. This has been particularly complex where local areas have sought to establish integrated provider arrangements and to transfer the employment of staff – with a host of very complex HR issues to resolve. While health services are typically available free at the point of delivery (either direct in an emergency or via a GP referral), social care is governed by a national framework for establishing eligibility to support and is often subject to means-testing. Over time, social care eligibility criteria have become increasingly stringent so that services are now often restricted to people with substantial or critical needs – and this makes it difficult for front-line staff to collaborate when operating two different systems with very different approaches to eligibility. Health and social care also both use different IT systems – and despite commitment to much greater use of IT, recent reforms seem to have focused on improving the use of technology within single organisations/systems rather than across the health and social care divide.

4.3 Financial

Health and social care both have separate budgets, raised in different ways. While the NHS is funded primarily through general taxation, social care receives some money from central government grants and from a national tax on businesses – but also raises a significant proportion of its own funds through local taxes and user charges. The current formula for funding local government is designed in such a way that an area wanting to increase its spending only receives the same central government grant, and so has to finance any rises in politically unpopular local taxes and charges (a system known as 'gearing' which is deliberately intended to keep costs down). In previous years, there have been concerns that social care has been the victim of 'cost-shunting' from the NHS (for example, with older people discharged from hospital much 'quicker and sicker' or with reductions in the availability of NHS funded long-term care). At the same time, the NHS has expressed concern that tightening eligibility criteria in adult social care has led to greater health need, with more older people left unsupported until they reach an immediate crisis in their health.

4.4 Professional

Accounts of joint working often contrast a 'medical model' (which emphasises a focus on individual biological conditions and on individual treatment and cure) with a 'social model' (which focuses more on social, environmental and attitudinal change in order to more fully include people with health and social care needs in society). In practice, this seems an oversimplification of a more complex reality, with a range of different health and social care professionals (each trained slightly differently and taught to value slightly different approaches and concepts) and significant fragmentation within both health and social care. As a result, there can be genuine disagreements between different professionals about the best way of responding to a specific need (often re-inforced by separate performance systems), different attitudes to taking or preventing risk, different views about the potential contribution and rights of

the individual service user and different language/jargon. Some professionals may also feel as if greater collaboration is threatening their professional skills and status, and as if their specific expertise and contribution is being downplayed. Historically, attempts to promote more effective joint working seem to have focused more on overarching organisational structures than they have on the organisational development required to work with different organisational and professional cultures.

4.5 Issues of status and legitimacy

With local government accountable to local voters and taxpayers, adult social care has often viewed itself as having an important local democratic mandate (and officers are overseen by elected local councillors). In contrast, NHS boards tend to be appointed rather than elected, and NHS organisations are (ultimately) accountable nationally to the Secretary of State. This is often described as a "democratic deficit" in the NHS, and there have been various discussions over time about mechanisms to develop greater local voice and representation within health care. At the same time, the NHS is a very popular national institution, with a large budget, significant popular/political support and powerful professions (especially the medical profession). In contrast, adult social care is much smaller and much less understood, with smaller, less powerful professions, a greater proportion of unqualified workers and an ambivalent public image. Whereas the NHS is seen as a universally positive concept based on strong values, social care has a more ambiguous role in combining care and social control – and therefore tends to be associated with higher levels of stigma (often re-inforced by means-testing and financial assessments). The NHS is also often seen as a single service (with an overarching identify and value base), while social care often appears more fragmented.

5 Key enablers

5.1 Shared vision

In recent years, health and social care have been given a legal duty to collaborate. Local areas have also been tasked with producing a series of joint strategic plans and negotiating a series of local targets and objectives that different agencies will work on together (Local Area Agreements). Regulation and inspection systems have also become more integrated, and these various changes have tended to promote more of a shared vision at a local level. In services for children, similar changes were accompanied by the identification of five high-level outcomes that all local services should be trying to achieve (known as 'Every Child Matters') – but a similar framework has not yet been developed in adult services. At national level, recent health policy has also included a greater recognition of the needs and contribution of social care – although some initiatives can still seem very focused on internal NHS issues and lack a whole system focus. Across England, a series of local health and social services have been responding to all these changes by working to develop a local shared vision – but this is complex, time-consuming and varies from area to area. Each area now also has a duty to conduct a joint assessment of the needs of the local population, and this in time may facilitate a more genuinely shared vision for the local community. In practice, the 1999 Health Act has created greater scope for local areas to work together to implement their shared vision (see section 8 below).

5.2 Clarity of roles and responsibilities

The difference between health and social care is poorly defined in legislation, and a range of previous policies tended to task local agencies with agreeing their respective responsibilities at a local level (for example around hospital discharge and continuing health care). More recently, there have been a series of national frameworks to help clarify some of these roles and responsibilities, and a number of joint targets have been developed to encourage greater joint working. However, it is often left to local areas to decide their local vision and agree roles and responsibilities themselves.

5.3 Appropriate incentives and rewards

A key barrier to date has been that most policy, budgets, incentives and rewards operate on a single agency basis – and this can hinder a genuinely multi-agency response to the needs of older people. This has begun to improve with more joint targets and joined-up inspection systems – but there remains a danger of some policies rewarding local agencies solely on the basis of their own performance and thus preventing them from prioritising joint working. A key issue (particularly around prevention and rehabilitation) is that the benefits of investment from one agency (often local government) are often felt by another partner (for example, the local hospital) – and tensions can arise if rewards aren't felt to be evenly distributed.

5.4 Accountability for joint working

Although local health and social care communities have a statutory duty to collaborate, this is primarily symbolic (with few legal sanctions available in practice to identify or penalise a lack of collaboration). Despite a growing number of joint targets, the key policy drivers are often single agency in nature and can pull partners apart rather than bring them together. Despite some positive changes, there is a danger of joint working being everyone's responsibility and no one's priority. At a professional level, there are similar risks – with different royal colleges and professional associations, different guidelines around standards and conduct and often very blurred lines of accountability (for example, is a doctor accountable to their Royal College, their peers, their Chief Executive or their patients – let alone to other health and social care professionals?)

6 The funding of long-term care services

Although estimates vary as to the cost of long-term care in England, a number of key statistics shed some light of the complexities of the current system of finance and governance (HM Government, 2008):

- Total state expenditure on care and support in England in 2006/07 was an estimated £20 billion (over 2% of GDP and 4% of total government expenditure).
- This includes some £13 billion state expenditure in England on adult social care (around £7 billion on over-65s and £6 billion on people aged 16-64), £3.4 billion on social security funding for disabled older people, £1 billion on social security payments to carers and around £2 billion spending on other social security and housing support-related activities for older people.

This does not include money that older people who fund their own care pay for their support nor money from the £100 billion NHS budget (which tends not to be broken down by age or by different user group categories in the same way).

More generally, the NHS estimates that people with long-term conditions (of which older people are the largest but not the only group) consume a significant proportion of health and social services. For example, around 80 per cent of GP consultations and two-thirds of hospital admissions relate to people whom the NHS describe as having 'chronic diseases' or 'long-term conditions' (Department of Health, 2004)

7 Financial sustainability

With an ageing population and rising expectations, the current system in England is widely perceived as financially unsustainable. Following high profile reviews in 1999 and 2006 (Royal Commission on Long-term Care, 1999; Wanless, 2006), a 2009 Green Paper has set out a series of options for funding institu-

tional forms of care for older people (and those of working age) – all of which involve a much greater partnership between the state and individual (HM Government, 2009). Some of the potential solutions proposed also involve a loss of social security entitlements in return for slightly more generous long-term care funding and/or a potential role for either voluntary or compulsory insurance. According to official estimates (HM Government, 2008, 2009):

- In the next 20 years, the number of people aged over 85 in England will double and the number over 100 will quadruple.
- In 20 years time, there could be a £6 billion funding gap.
- If the current system remains unchanged, then the cost of disability benefits could rise by almost 50 per cent in the next 20 years, while the cost of long-term care could rise by 17 per cent by 2027/28.

Taken together, these statistics have raised the profile of the funding of services for older people – with significant national policy development and consultation underway as part of a 'Big Care Debate'. To date, however, the focus has been on funding the care home places of a relatively small number of older people admitted to permanent residential/nursing care – not on the bulk of older people with health and social care needs living in the community. More recently, the November 2009 Queen's Speech has included legislation to enable free personal care for people with the highest needs living in their own homes – although there is little clarity as yet as to what this might mean in practice. Underpinning these debates is a clear statement from government that (HM Government, 2008: 8):

> *"Society is going through huge change. People are living longer than ever before, and the proportion of older people in our society is growing. We have different social values, and we expect more choice and control over all areas of our life, including public services. And too often the existing system does not live up to the expectations of those who depend upon it… A radical rethink of the care and support system is needed to address these challenges. Otherwise, it is likely that families, including dependent children within the family, will be under pressure to provide inappropriate levels of care, and in some cases people will go without support. If we fail to get a grip with these long-term issues we will fail to provide quality of life for potentially large groups of people, and consequently demand for NHS services will increase inappropriately."*

8 Good practice

From England's experience of the governance and financing of long-term care for older people, there are three potential areas of good practice to share with other systems:

- Although the current government has been criticised for not responding to the needs of an ageing population during previous reviews in 1999 and 2006, it has now recognised the urgency and started a national debate about future care funding. This has included a formal Green Paper, with a dedicated website, a series of regional events, a regular blog from the national Director-General of Social Care and an opportunity for anyone viewing the website to submit comments or questions online (see http://careandsupport.direct.gov.uk).
- In 1999, the Health Act gave local health and social care communities the legal powers to pool aspects of their budgets, to delegate commissioning responsibilities for a particular client group to a

lead partner and to create integrated service providers. While these flexibilities do not remove the underlying health and social care divide, they have given local areas greater ability to create locally appropriate and agreed solutions to the problems of joint working.

- A series of recent reforms have now created an integrated health and social care regulator (the Care Quality Commission) and a new duty for local partners to carry out an annual Joint Strategic Needs Assessment of the local area. With broader partners also coming together through Local Strategic Partnerships to negotiate local priorities (via Local Area Agreements), there is scope for much greater joint working in future.

9 Ongoing tensions

At the same time, the English system continues to struggle with a series of ongoing tensions:

- Despite positive progress, England's health and social care divide continues. While local partners have greater scope to blur this, the fact remains that the system is still based on the assumption that it is meaningful to distinguish between people who are sick and those who are frail or disabled. However appropriate this may or may not have been in the past, it seems increasingly difficult to maintain such a division in an era of long-term conditions and with an ageing population. In spite of recent policy proposals to reform long-term care, the government to date has stopped short of revisiting the underlying health and social care divide. In particular, many of the incentives in the current system do not feel fully aligned with desired outcomes – and achieving this alignment could arguably be a powerful force for change.
- Although the 'Big Care Debate' is a laudable attempt to involve members of the public in current policy decisions, it arguably falls short of the national debate that many commentators feel is needed. What seems to be at stake here is the need to rethink and potentially replace the 1940s assumptions on which current welfare is based with an approach and an ethos more in keeping with how we live other aspects of our lives in the twenty-first century. In spite of an admirable attempt, the government has not yet been able to develop this sense of a national debate or a new settlement for the welfare state as a whole. Clearly this is a two-way process, involving the public and the media as well as government – and it remains to be seen whether England as a society is able to debate these difficult issues and reach some sort of consensus.
- Many previous policies have sought to compel and/or encourage local areas to form more effective partnerships, without sufficient recognition of the complexity that this entails. All too often the focus has been on changing and merging organisational structures, rather than on developing more joined-up practice at ground level or on working with different organisational and professional cultures. There is also an important role for local areas to do the best they can to overcome some of the difficulties inherent in inter-agency working, to disseminate good practice and to learn from other areas. Without this, there is a danger that everyone waits for national action rather than every level in the system taking responsibility for finding and embedding potential solutions.

10 Embedding good practice in everyday practice

Since the election of the current New Labour government in 1997, policy makers have used a range of different incentives, sanctions and legal frameworks to try to embed good practice in everyday practice. These include:

- New statutory duties to collaborate (which have some symbolic value, but arguably lack the detail or sanctions to change front-line practice).
- The creation of new national bodies to identify and disseminate what works, both in health care and social care. While the social care body (the Social Care Institute for Excellence or SCIE) is small and has no authority to enforce compliance with good practice, the NHS body (the National Institute for Health and Clinical Excellence or NICE) has greater powers, but its decisions have sometimes been challenged by patient groups and/or by pharmaceutical companies. NICE has also been tasked with speeding up its procedures to give quicker opinions on the cost-effectiveness of new medications.
- The provision of additional funding, to boost social care spending and to bring the NHS up to European levels of expenditure. While this has led to a number of improvements, the jury remains out on the extent to which the changes that have taken place are sufficient to justify this sustained investment. Such spending will also cease following the recent global recession.
- The use of targets, national inspectorates and star rating systems to compel changes in focus and practice. While these have produced some changes, they can be very demoralising for front-line staff and run the risk of distorting local priorities.
- The provision of consultancy support and development through a series of arms-length bodies (such as the Change Agent Team or the Care Services Improvement Partnership). These have since been abolished and the resource devolved to regional level.
- More recently, there has been an even stronger emphasis on strategic commissioning and on the promotion of choice/competition via a series of quasi-markets – although concerns remain as to whether this might make collaboration across the whole system even harder in future.
- In addition, social care in particular has promoted the concept of direct payments and personal budgets (encouraging people to take greater control of their own support by receiving more individualised forms of funding). While these seem very positive so far, they involve significant cultural change and it remains to be seen if they can transform the system as a whole.

Reviewing social policy over recent years, one prominent analyst (and a former health advisor to the Prime Minister) has described the options open to the English government in terms of (Le Grand, 2003, 2007):

- Trust: relying on public service professionals to do their best for people using services.
- Targets: seeking to encourage/compel change through greater use of national targets.
- Voice: giving people using services greater say in how they are run and enabling them to express dissatisfaction.
- Choice and competition: giving people greater ability to choose which service they wish to use and thus giving an incentive to all services to improve their performance and responsiveness.

While Le Grand is particularly keen to explore the implications of the latter (which he feels has been underdeveloped compared to the other approaches), he argues that a more nuanced blend of these

different approaches may well be required for current and future reform. With a possible change in government predicted at the next general election and in a challenging financial context, the jury remains out on the exact mix of these different approaches that may be chosen.

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