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SOCIAL POLICY RESEARCH UNIT

# A New Vision for Adult Social Care: Scoping Service Users' Views

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## Introduction

This paper has been commissioned by the Department of Health from the Social Policy Research Unit (SPRU) at the University of York as a contribution to the debate on the future of adult social care.

SPRU has an international reputation, established over 30 years, for conducting research that:

- Influences policy and practice, in order to improve the lives of vulnerable people
- Is methodologically rigorous and ethically sound
- Reports the views and experiences of service users including those often neglected in research, such as people with communication difficulties
- Recognises that many people have support needs that cross professional and organisational boundaries.

Over the past ten years, SPRU has carried out a research programme, funded by the Department of Health, on the Outcomes of Social Care. This research programme has identified the outcomes that disabled adults, children and their families aspire to achieve from using services; and investigated ways of introducing outcomes-oriented approaches into routine service practice. The expertise derived from the DH-commissioned Outcomes research programme underpins and informs the scoping exercise reported in this paper. However, this paper draws on a much more extensive range of documentary material and combines this with rigorous policy analysis.

The aims of the paper are:

- to ascertain the ideas and views of a range of service user and other organisations
- to collate and synthesise these views in an accessible format
- to consider how far these views are compatible with the proposals for children’s services contained in *Every Child Matters.*

In order to ascertain the ideas and views of service users, we made contact with an extensive list of organisations that represent the interests of service users. We aimed to reflect the entire spectrum of potential users of adult social care services and included organisations representing disabled adults, older people, family carers, drug and alcohol users and other groups of service users. We also included organisations that are often commissioned by local authority social services departments to provide specialist services to specific groups of adults, such as Family Welfare Association, Family Service Units and Anchor Housing. Additionally, we included organisations like the Audit Commission and the Joseph Rowntree Foundation, whose publications are known to reflect exceptionally high levels of service user consultation and involvement. The full list of organisations contacted is listed in Appendix 2.

Initially the website of each organisation was visited to ascertain if any relevant recent publications were available. This was frequently followed up with telephone or email contact. Organisations were asked to supply any recent publications or reports, whether officially published or ‘grey’ material, that reflected their members’ experiences of adult social care services and/or that contained ideas for reform and change from service users’ perspectives. Given the short timescale available for this work, we were only able to allow three weeks for organisations to respond to our request. The organisations from which reports and publications were obtained are also indicated in Appendix 2.

As Appendix 2 shows, the responses from organisations varied. In general, we were able to obtain a much greater range of material that reflects a new vision for social care from the perspectives of older people than for other groups of adult social care service users. User organisations such as Age Concern, inspection bodies like the Audit Commission and research funders like the Joseph Rowntree Foundation have all undertaken or sponsored a considerable amount of work in recent years that sets out new agendas for older people’s services. To some extent this imbalance is reflected in the synthesis presented in this paper. However, many of the principles underpinning the new agenda for older people’s services are similar to those that have been articulated over the years by younger disabled people and the Independent Living Movement, so we are confident that the ideas reported in this paper have wider applicability.  Nevertheless, it will be important to ensure that the concerns of smaller groups of adult social care service users are not marginalised in any new vision for adult social care.

The paper is in three sections:

- Section 1 looks at the desired outcomes of a new approach from the perspective of users of services.
- Section 2 identifies the service principles that would underpin the accomplishment of the outcomes identified in Section 1.
- Section 3 identifies some implementation issues concerned with matters of structure and process.

In the interests of accessibility, the individual documents that we have used are not systematically quoted and referenced in the body of the report, but all are listed at the end (Appendix 1). It should also be emphasised that this report is not comprehensive in respect of the range of potential stakeholders and the published evidence – this was simply not possible within the time available. Rather it attempts to identify a framework - key issues, themes and patterns that recur across the literature and across the different groups of service users. While further illustrations and amplifications are always possible, we nevertheless believe that the identified framework is robust and enduring.

# Section 1: Ten Outcomes

## The nature of outcome-based approaches

Services developed on a sound understanding of what people believe, want or need are more likely to deliver intended outcomes effectively. However, because social care users tend to be seen as needy, dependent and frail, there is a danger of failing to listen to their views and hopes, with services taking a correspondingly narrow perspective. In particular, the emphasis of much service provision in both social care and the NHS is upon a model of ‘deficit and dependency’ rather than ‘wellbeing and independence’, in addition to an established culture of supply-led rather than outcomes-driven provision. The starting point for a new vision therefore is the identification, in association with adults who require social care, of the outcomes that service support should achieve; these should include an emphasis upon the maintenance of social identity and social roles. The role of relevant agencies would then be to show how their activities contribute to meeting these user-defined outcomes, rather than focusing inwardly upon their individual service objectives and targets.

It is important to be clear about the conceptual framework that comprises an outcomes-based approach. Outcomes refer to the effects or impacts on the welfare of service users and should be distinguished from outputs, which are, strictly speaking, service products. Ultimately an outcome can be defined in strictly subjective terms as the extent to which an individual feels his or her needs have been met. However, this cannot absolve decision-makers from ensuring a distribution of resources that is fair in terms of the opportunities offered to people in similar situations. Indeed, the US analyst Mark Friedman, who has been influential in recent developments in children’s services, argues that outcomes are the effect on the wellbeing of whole populations, without regard to whether anyone is receiving a service.

An important concern in developing a new vision is the extent to which it is possible (or even desirable) to identify outcomes that have generic applicability across the full range of adult social care user groups. The general consensus emerging from the literature is that most groups differ little in their wants and needs – indeed some of the representative groups strongly challenge the distinction made in the SCIE consultation between ‘adults of working age’ and ‘older people’, arguing that this is a discriminatory premise. Others also argue that as many needs, concerns and policy implications are common across different conditions and groups, so making a real impact on improving lives requires a general approach based on a few fundamental principles rather than a restricted focus upon specific conditions.

## Ten outcomes in adult care

Our review of relevant literature suggests ten broad outcomes from social care and related services can be identified (Box 1). Although much of this literature focuses on older people, we believe these priority outcomes are consistent with the aspirations of other groups of adult social care services users.

**Box 1: New Vision for Adult Social Care: Ten Outcomes**

1. Maintaining independence
2. Keeping clean and comfortable
3. Enjoying a clean and orderly environment
4. Being safe
5. Access to social contact and company
6. Keeping active and alert
7. Living healthier and longer lives
8. An adequate income
9. Opportunities to contribute to the community
10. Feeling valued

### 1. Maintaining independence

One recent survey of older people's definitions of quality services concluded that, above all, older people want control over their daily lives. However, it is important to unpick precisely what is meant by 'independence'. Independence has different meanings, depending on whether a medical or a social model of disability is being used to understand and establish need. A focus on physical functioning or health status reflects a 'medical' model of disability in which the condition is defined in terms of physical malfunctioning that requires medical intervention. The 'social' model, on the other hand, focuses on the attitudinal, institutional and environmental barriers that disabled people encounter within society.

Thus, rehabilitation and intermediate care associated with the medical model aims to normalise the limiting effects of impairment in order to enhance a user's ability to undertake 'activities of daily living' unaided. In contrast, the social model concentrates more on devising a range of strategies in order to increase a user's sense of autonomy and belonging, and to enhance her/his sense of authenticity and identity as a disabled person. The actual balance between 'doing what you want to do' and 'doing things for yourself' is likely to reflect an individual's capabilities, social context and expectations as well as her/his ability to 'manage' a disabled or stigmatised social identity. However, although there are significant differences between the two approaches, for the individuals concerned this may be less important than the capacity to be in control and make their own decisions about their lives. Ensuring independence in this latter sense is arguably the most important outcome for adult social care service users.

### 2. Keeping clean and comfortable

This includes being personally clean and presentable in appearance, having suitable arrangements for using the toilet or managing incontinence and other basic hygiene needs (e.g. toenail cutting), having clean clothes and bedclothes, and eating and drinking normally as far as health allows. Those not experiencing illness or disability may take the meeting of such needs for granted, and would accord this outcome a lower significance. However, providers of social care have increasingly focused on personal cleanliness and comfort, with some studies finding significant levels of user resentment at the unavailability of basic domestic help that also contributes to keeping clean and comfortable.

### 3. Enjoying a clean and orderly environment

This relates to the previous point on availability of cleaning services. The literature indicates the importance of this outcome to certain groups, particularly - though not exclusively - older women. This is not just because people value a clean environment in itself, but also because a ‘dirty’ home or untidy garden can be experienced as a reflection on their reduced capacity to manage their own affairs, thereby signalling a breach in the sustained sense of identity consistent with their previous experience of self.  Since vulnerable adults may spend greater periods of time in the house, this assumes greater significance. The extent to which there is recognition of the importance of such ‘lower level’ support will be a recurring theme of this report.

### 4. Being safe

This relates to confidence that help is accessible in any emergency, as well as to generally feeling secure and protected from possible harm. Feeling safe operates at both an individual level (personal safety) and a collective level (community safety). At the individual level, there may be situations where people wish to accept risks that give concern to relatives or to service staff. At the collective level there will be perceptions of feeling safe from acts of crime and disorder.

### 5. Access to social contact and company

Being part of a community where people care about and look out for each other is crucial to achieving a good quality of life. This implies some capacity for getting out of the house for shopping, making contact with others and participating in community life. At a minimum this means averting the severe social isolation that results when physical or mental difficulties prevent someone leaving the home. Such isolation can have serious adverse effects upon mental health, so that service users with minimal social networks place a very high value on the social aspects of visits by care staff.

### 6. Keeping active and alert: Having something to do

In general, people seek opportunities to preserve their mental and physical health by access to leisure, social activities, lifelong learning opportunities and so forth. This is valued both as an end in itself and as a means of achieving the social interaction identified above as an important quality of life outcome. For those not in independent living arrangements, keeping active and occupied can be a critical issue; a lack of meaningful activity in residential settings has been critically viewed by some, especially those in younger age groups who experience little consideration of their personal preferences, desires and future aspirations.

### 7. Living healthier and longer lives

A major achievement of the last century is that people are living much longer, raising the opportunity and challenge of vitalising the later life stages by ‘adding life to years’ – a process sometimes conceptualised as ‘active ageing’. Most people want to lead an active and fulfilling life for the whole of the life term, even if their health is failing; if the right support is not available, poor health can restrict people’s sustained ability to live life to the full. In this regard, support needs to go beyond the bounds of conventional clinical and care issues. This incorporates ‘upstream’ preventive interventions that help to enhance health and wellbeing, including better access to mainstream health care for groups that have suffered some exclusion, such as people with learning disabilities.

### 8. An adequate income

This is the prerequisite for meeting many needs – nutritious food, adequate heating, independence, mobility and participation in the community largely depend on being able to afford the services that make access to them possible. The elimination of poverty and greater financial independence raises questions about the adequacy of state benefits as well as better information and ease of access to current benefit arrangements.

### 9. Opportunities to contribute to the community

More people wish to have the opportunity to work or have access to other income-generating opportunities. A third of people between 50 and state retirement age are not in paid employment, and less than a third of the fall in older people’s employment has been voluntary. This can give rise to considerable costs in terms of health, income and social exclusion. Those who undertake caring roles also need opportunities to engage as workers and members of the community in other ways. However, it is important to avoid any inference that people who are not working are either failing to fulfil their role as a citizen, or are in need of some form of care - alternative means of making a contribution to the community and society will also be needed.

### 10. Feeling valued

People in need of support have spoken of not feeling valued, of no longer feeling at home in familiar neighbourhoods, or of being described as ‘bed blockers’. Some stakeholders take the view that current social services provision, sometimes unwittingly, is structured in a way that encourages discrimination, most apparently in the lower financial ‘ceilings’ applied to home care services and the exclusion from the Independent Living Fund of people aged 65 and above. Other stakeholders point to assumptions about a decreased need for social engagement after a certain age – the recently overview of research on older people funded by the Joseph Rowntree Foundation (JRF) reports older people’s frustration about services, social and media discourses which they feel consistently refer to financial ‘burdens’ and risk management. The JRF overview concludes that:

> *The central point which comes through all of the projects is that current policies, social images of older people, services, even some of the newer initiatives in policy and practice, all struggle to break away from the deficit model.*

This implies the need to confront stereotyping and other forms of discrimination, possibly through a new equalities framework.

## Every Child Matters ‘Read Across’

The ten outcomes identified above are sufficiently broad to be applicable, to a greater or lesser degree, to all of the main client groupings with which social care is concerned – older people, people with physical impairments, people with learning disabilities, people with mental health problems and family carers. Developing such an outcomes-driven approach is also consistent with the changes being proposed for children’s services by the *Every Child Matters* reforms. Here, five outcomes for children and young people have been identified:

- *Being Healthy:* enjoying good physical and mental health and living a healthy lifestyle;
- *Staying Safe:* being protected from harm and neglect; growing up able to look after themselves;
- *Enjoying and Achieving:* getting the most out of life and developing broad skills for adulthood;
- *Making a Positive Contribution* to the community and society; not engaging in anti-social or offending behaviour;
- *Economic Wellbeing:* overcoming socio-economic disadvantage to achieve full potential in life.

There are strong resemblances between the ten outcomes for adult services identified in this report and the five outcomes for children and young people (Box 2).

**Box 2: Outcomes for adults and children & young people compared**

| **Children's services** | **Services for adults** |
|---|---|
| Being Healthy | • living healthier and longer lives<br>• keeping active and alert<br>• maintaining independence |
| Staying Safe | • keeping clean and comfortable<br>• enjoying a clean and orderly environment<br>• being safe |
| Enjoying and Achieving | • maintaining independence<br>• access to social contact and company<br>• feeling valued<br>• enjoying a clean and orderly environment |
| Making a Positive Contribution | • keeping active and alert<br>• employment opportunities<br>• maintaining independence<br>• being able to contribute to community life |
| Economic Wellbeing | • an adequate income<br>• employment opportunities<br>• feeling valued<br>• maintaining independence |

In summary, there is already a great deal of evidence of the sorts of outcomes that adult users and carers feel contribute to a good quality of life. These issues are also being explored through separate listening and consultation exercises currently being conducted by DoH, DWP, ODPM and others. Nevertheless, it may be that there are grounds for undertaking further, more structured research exercises – the *Every Child Matters* outcomes, for example, were developed on the back of a specific consultation exercise with children and young people. It is important not to rush this part of any emerging vision, for if the outcomes are misjudged then the entire mission is doomed to fail. However, the evidence to date suggests that:

- there is a broad consensus about the key outcomes for adults
- there is a close relationship between outcomes for adults and children respectively.

## Section 2: Ten Service Principles

The user outcomes identified in the preceding section are necessarily couched at a high level of generality, but they do hold clear implications for the principles upon which models of service delivery will need to be based. This section identifies ten service principles that flow from the user outcomes identified in Section 1. These are shown in Box 3 below.

**Box 3: New Vision for Adult Care: Ten Principles of Service Delivery**

1. A whole person model
2. A whole systems model
3. A comprehensive model
4. A user empowerment model
5. A reciprocal model
6. A checks and balances model
7. A personalised service model
8. A choice and diversity model
9. A social capital model
10. An implementation model

### 1. A whole person model of service delivery

There is widespread agreement that improving the quality of life for vulnerable adults means tackling social exclusion on a broad front, from low incomes and poor housing to the promotion of good health and participation in society. At minimum, this implies an approach that encompasses two dimensions of rehabilitation: services that prevent or offset the need for more costly and intensive services; and strategies that promote quality of life and engagement with the community. Such an inclusive model is in line with the analysis of responses to the first round of consultations on ‘the new vision’, which concluded that ‘*we need a “public health” whole population approach focussing on the 85 per cent of the various groups with whom adult social care services are not in contact, as well as the 15 per cent with which they are’*. Traditional partnerships between the NHS and social care form but a relatively small part of the service interfaces and partnerships required by this principle. The JRF research programme on older people claims that the current welfare-rationing approach gets in the way of adopting a broader remit that treats older people of all economic groups as citizens and consumers, and which draws in a wider set of service partner organisations, including those from the private sector.

## 2. A whole systems model for service access and delivery

All stakeholders and constituencies are agreed that joint working is an essential part of any future vision; the challenge is to refine this approach in order to meet the requirements of the socially inclusive model outlined above. This implies a 'whole systems' approach, rather than specific, *ad hoc* partnerships - a mode of working that is not yet well developed. The evidence suggests that users are currently confused about what services are available and who the providers are, and are anxious to see better joined-up working. In a recent publication, Turning Point uses the analogy of a faulty car to illustrate the experiences of people with serious health or personal problems when trying to get help:

> *Imagine trying to get your car fixed after it breaks down and finding that you have to take it to a different garage to fix each part – one to change the brake cable, another to fix the windscreen, a third to change the tyres and so on. Even worse, each garage is in a different area and none of them share information, so you have to repeatedly explain the problem and fill out separate forms at each visit*.

Amongst others, Primary Care Trusts have a crucial role in contributing to a new vision for adult social care. However, their priorities are currently divided between the implementation of 'payments by results', the achievement of centrally-imposed performance targets, increasing patient choice and servicing debt. Now there is a new factor in the equation – practice-led commissioning – and it is unclear whether this will serve as a rich opportunity or a complicating hindrance to a whole systems approach.

Joining-up is one of nine competencies that the Government has identified for professional policy making, and this requires building alliances around shared goals rather than around organisational structures or existing systems. Rather than constantly modifying internal organisational frameworks, the need is to align existing policies and structures – defining responsibilities, introducing appropriate financial incentives and clarifying accountability arrangements. The aim should be to create multiple legitimate routes into a broad range of services from a variety of sectors, that reflect the diversity of people's circumstances and expectations. All of this requires more robust joint working arrangements than have hitherto been routinely achieved.

## 3. A comprehensive model: Upstream and downstream

In the past, services have tended to be partial rather than comprehensive in character, with a short-term focus upon targeted populations. This is not an intrinsically flawed approach. Typically, the starting point for a comprehensive approach is the realisation that immediate challenges, such as reducing hospital admissions, average lengths of stay, attendance at A&E and use of GP services, are best addressed by a whole systems model that also includes low-level, interim and early intervention wherever possible. However, tensions have developed between comprehensive and targeted models, with the neglect of preventive or 'lower level' services seen by some as a consequence - possibly unintended - of the community care reforms of the 1990s.

The demography of adult care makes it difficult to sustain a highly targeted strategy. Over 17 million people in the UK are estimated to be living with a long-term condition like asthma, diabetes or cancer and nearly half have more than one condition. It is estimated that 60 per cent of GP consultations relate to chronic disease management, and that patients living with a long-term condition or its complications use over 60 per cent of hospital beds. In contrast, there are 3.5 million older people living at home, compared to 100,000 acute hospital beds. To ignore such a potential groundswell of need until crisis point is reached is not a viable option.

There is now a growing consensus on the need to take a more comprehensive perspective on service delivery. The emphasis here is upon the high value placed upon relatively small amounts of assistance that can make a lot of difference to people's capacity to carry on independently; failure to do so leads to great stress, unnecessary dependency and ultimately higher costs to the taxpayer. It is noted, for example, that the longer people with the early symptoms of severe mental illness remain untreated, the greater the opportunity for serious social and physical harm or for negative contact with the criminal justice system. This view is reflected in the 'inverted triangle' model of care that has been proposed for older people, in which the promotion of wellbeing is at the top. This graphically illustrates the importance of extending universal services to all adults, a perspective which is now deemed to be crucial to the operation of all agencies.

## 4. A rights based model: User empowerment

The existing legislative framework for social care for adults is based on concepts rooted in the Poor Law and involves a narrow definition of entitlement to need, combined with financial means testing. Needs assessment that focuses on what people *cannot* do is still the route to accessing services, and this is usually accompanied by an assessment of income that remains highly problematic to many service users. Those seeking independent living arrangements also point out that practically all existing support systems place some kind of ceiling - in terms of cost or eligibility criteria or both - on the level of resources at which independent living is deemed viable. Older people are unhappy about the time limits placed on intermediate care, complaining that after six weeks their services are withdrawn or they are expected to pay for 'non-NHS' components of their support. A recent survey of independent living in later life (conducted for DWP) concluded that:

> *There was an issue about asking for help among people who would like to have received particular services, but felt uncomfortable or unconfident about seeking these out, and who were also uncertain of their eligibility. Some interviewees felt there was a stigma associated with claiming statutory*

> *services and there were also perceptions that asking for help was an admission of failure*.

An alternative approach would combine a social model of disability and ageing with an emphasis upon rights as well as needs - ideas pioneered by the disability lobby, but applicable across other groups of adult social care service users. The current framework, based largely upon targeted and highly discretionary access arrangements, leaves service users in a relatively powerless position. In other countries, such as the Netherlands, Germany and Austria, rights and entitlements to non-medical long-term care are closely linked to concepts of citizenship. These are much more inclusive systems and individuals who are eligible by virtue of their needs for help and support are entitled to guaranteed levels of support. One recent UK proposal is to introduce a legal right for disabled people to choose to live in the community rather than in residential care. Naturally, this has financial - and therefore political - implications. However, from the point of view of the service user, such rights would transform the nature of current debate and social care practice.

User empowerment can also be increased through the development of user-controlled services. Disabled people’s criticisms of professional attitudes and practices has resulted in a small number of Centres for Independent Living - organisations controlled by disabled people themselves and providing such services as information, advocacy, peer support, housing advice, personal assistance support and work training and advice.

A third strategy for increasing user empowerment is the promotion of collective user ‘voices’ - and of effective service responses to those voices. A recent study of housing decisions in old age (in which older people were themselves the researchers) found that:

> *Older people want to have their voices heard and they want action. This is the message that older people want emphasised above all others. While there seemed to be plenty of evidence of being asked for their views, there was much less evidence that they had been listened to, and that actions were taken as a direct result.*

A similar message emerges from the JRF research with older people:

> *The most crucial message from the programme as a whole is that successful change depends on the meaningful involvement of older people in defining quality of services and quality of life.*

## 5. A reciprocal model: Giving and receiving

The dependency and deficiency model can too easily give the impression of a uni-dimensional system of exchange in which those with identified needs receive support from those without, *via* local and national redistributive mechanisms. A reciprocal model, by contrast, would emphasise the contribution that has been, is, or could be made by those who are also in receipt of services and support. Some older people see the receipt of help in later life as part of an implicit, reciprocal contract with the welfare state, to which they have contributed all their lives. This approach also implies a fundamental reappraisal of the implication that independence is good and dependence is bad. A recent survey conducted by the Audit Commission, for example, found that the only area in which respondents were willing to pay more council tax was for elderly people to have better services. Respondents felt that older people '*had worked all their lives*' and should not have to bear additional support costs themselves.

Others are keen to emphasise the current and potential contributions of adult social care users. For example, it has been pointed out that older people make particular social contributions in areas such as volunteering; caring for grandchildren, relatives and neighbours; and in citizenship and community roles such as local community representatives and organisers of community groups. Adults and older people, including those who need some support, also have a lifetime of experience upon which to draw and often have internal resources and strategies that need better recognition and utilisation. Promoting social inclusion involves recognising and supporting people in these various roles, including roles as employees and employers, and these are issues that cross all adult user groups. A relatively small amount of support may enable individuals to make disproportionately large social contributions to their families, local communities and wider social networks.

### 6. A checks and balances model: Equity and localism

At central government level, there seems to be a recognition of the limits of top-down policy making and implementation. The Department of Health has declared that in future it will set direction, provide resources and 'lead the transformation' but will no longer attempt to manage service delivery - it will 'steer more and row less'. This is consistent with an outcomes-led approach, with localities judged on the extent to which they deliver on outcomes but left free to determine how best to do this. However, there is some uncertainty about the extent to which 'the new localism' can be taken at face value and, indeed, about the extent to which it is desirable. In the case of the NHS, it has been argued that decentralisation continues to take place in the context of strengthening central power to make the service more efficient and responsive to patients - Public Service Agreements are the most evident manifestation of the latter tendency.

Whilst some have argued that the key to unlocking new ways of commissioning and working in adult care is to increase the proportion of local budgets that are truly discretionary, others are mindful of the potential for inequity in terms of access to services. The Long-term Medical Conditions Alliance, for example, calls for improvements in equality of access to the most effective treatments and services and an end to rationing by geography or postcode. The National Audit Office reported those with implementation remits valuing freedom to develop local solutions, but also seeking help and guidance. Finding the right balance between equity and localism is the essence of a ‘checks and balances’ model - national drivers can do only so much, and there is a need also to support locally-driven approaches and standards.

Finally, there are also issues of ‘checks and balances’ in relation to the participation of local service users - an issue highlighted above in Service Principle 5. Consultation and involvement in service developments requires some standards - involving people right at the start; involving more than one or two token representatives; allocating the necessary time, resources and commitment for involvement; and being clear about exactly what can be influenced. There are several classifications of empowerment in the literature with the potential to be applied to decision-making processes. One model draws upon Arnstein’s long established ‘ladder of participation’:

| | |
|---|---|
| **HIGH** | Users have the authority to take decisions |
| ↑ | Users have the authority to take selected decisions |
| | Users’ views are sought before decisions are finalised |
| ↓ | Users may take the initiative to influence decisions |
| | Decisions are publicised and explained before implementation |
| **LOW** | Information is given about decisions made |

This model is similar to that proposed by the Audit Commission:

| | | |
|---|---|---|
| **HIGH** | *Devolution:* | providing resources and allowing people to decide how to use them |
| ↑ | *Delegation:* | providing a framework that people use to decide for themselves |
| | *Participation:* | discussing issues that need to be tackled and working on the solution together; usually ongoing |
| ↓ | *Consultation:* | stopping and asking people for their views before the final decision is made; usually one-off |
| **LOW** | *Information:* | letting people know about services or plans |

Thus, while the nature and focus of user involvement will necessarily be determined locally, central guidance and standards may be required to make sure this is effective.

### 7. A personalised service model

Moving away from a ‘one size fits all’ approach (alleged to characterise the post-1945 welfare state) towards more personalised services has wide support across all stakeholders and is also reflected in research with service users. The JRF programme with older people, for example, concluded that:

> *At present, despite a seeming commitment to a more modern approach, often little has changed in service delivery since the Community Care Act in 1990 ... Yet the constant message through all the projects has been that approachable and flexible local services could make a substantial difference to people’s lives.*

The Partnership on Long Term Conditions puts it this way:

> *People with long term conditions want tailored services delivered in an environment that meets their needs; services which recognise that they are a person, not just a series of separate diagnoses; services which take account of their emotional and psychological wellbeing as well as physical needs; and services which reflect their individual choices and personal preferences at different stages of their life and disease progression.*

Many users’ circumstances are not stable and involve repeated renegotiations and adjustments, but services have difficulty responding to these changing circumstances. Improvements in quality of life are arguably more likely where the balance of power is tilted in favour of the service user rather than the service provider - the empowerment model outlined above. In the case of long-term conditions, this involves greater recognition that service users themselves are the ‘experts’ about their condition, about managing in their lives, and about what makes for good quality services. However, while the role of ‘expert user/patient’ is widely welcomed, this still needs to be backed up by appropriate professional advice, treatment and care - some people feel they have no choice but to manage their own condition, and want more support at difficult times. This service principle may well be given effect through direct payments, but it is important to also explore other models such as advocacy and brokerage.

### 8. A choice and diversity model

Choice is another key principle of public service reform and, at an abstract level, this notion is widely supported, along with the implied corollary of increased diversity of providers. A recent Audit Commission report on choice in public services found that whilst the general public considered choices in some public sector services to be relatively unimportant, there was greater support for choice in relation to services for older people living at home. Moreover, there was higher demand for choice from the least privileged people (social classes D and E), women and service users, all of which suggests a choice model could have redistributive consequences that help to reconcile choice with equity.

However, ultimately it is not the principle of choice that is important but whether services can be responsive to individual choices. Thus allowing users to choose service providers may lead to more responsive services, but choice may not be a sufficient incentive on its own. More broadly, choice cannot be unlimited in its scope or use. Questions of capacity, of the collective good, of the availability of enough information, and of costs as well as benefits for individuals also need to be weighed up.

## 9. A social capital model

A large amount of social care is provided within families, but the increasing dispersal of family members also triggers the need for new types of support systems within the neighbourhood and community. Putman's concept of 'social capital' is important here; stocks of social capital such as trust, group norms and self-help networks are 'public goods', created and owned by the community and complementary to investments in physical capital, financial capital and human capital. Moreover, social capital can be self-reinforcing and cumulative, with successful collaboration in one endeavour building connections that make further collaborations possible. There is some tension between social capital and a model of individually-driven choice; Putnam argues that excessive emphasis on market-based services has eroded social capital and that the emphasis on individual choice is misplaced when those choices are destructive of public goods like social capital.

This argument is consistent with the view that services work best where people who need support are able to draw on existing sources of help and support and retain existing friendships and social links. Age Concern has used the concept of social capital to measure the development of cooperation, informal relationships and participation in community roles amongst older people in rural communities, while researchers at the University of Leeds have used similar ideas in supporting and evaluating a neighbourhood scheme in Leeds. In the latter case, neighbourhood groups rooted in the community and underpinned by values of neighbourly support, reciprocity and the engagement of older people at every level were found to make a significant contribution to the wellbeing of older people. It has also been argued that how people make sense of any losses they experience as a result of ageing or disability depends partly upon the social and other resources they can mobilise to reduce the impact. At an individual level these resources are closely bound up with stocks of social capital and sustaining these stocks over time may involve continuing participation in social and community life. There are implications here for revisiting community development approaches to social care - a long neglected dimension of local service support.

## 10. An implementation model

The DWP's Link-Age strategy on developing networks of information services for older people states that the key to delivering improvements is threefold - developing a coherent vision of the future; building effective partnerships that span traditional organisational boundaries; and developing realistic plans for delivery. Thus far this report has focussed upon the first of these principles; the remainder of the report will concentrate upon the latter two. However, the evidence suggests that these are characterised by a significant implementation gap. The Audit Commission, for example, concluded in its report on independence and wellbeing for older people that:

> *Implementation remains an aspiration for most communities. Older people's needs and views have been clear for some time, but communities have found it difficult to refocus services towards promoting wellbeing and independence*.

The final part of this report will explore some of the implementation issues involved.

## Every Child Matters 'Read Across'

There is a high level of consistency between the service principles for adults and those for children as proposed by the *Every Child Matters* reforms. These are outlined in Box 4.

**Box 4: Service principles for adults and children & young people compared**

| **New vision for adult care** | **Every Child Matters reforms** |
|---|---|
| Inclusive Model | • clear focus on 'every child' not just children in need of protection<br>• outcomes based in citizenship and community engagement |
| Coordinative Model | • legal duty of cooperation<br>• expectation of strategic partnering and operational coordination<br>• strong push for information sharing |
| Comprehensive Model | • emphasis on both upstream and downstream interventions<br>• 'inverted triangle' model |
| Rights and Empowerment Model | • emphasis on involving and engaging young people in decisions that affect their lives |
| Reciprocal Model | • key outcome is children and young people making a positive contribution to the community and society |
| Checks and Balances Model | • focus on outcomes and integrated inspection: steering not rowing ...<br>• but comprehensive central regulation and guidance is pending |
| Personalised Service Model | • common assessment framework<br>• lead professional<br>• individual care plans |
| Choice and Diversity Model | • some tension between focus on collective choice and 5 year Education Strategy focus on individual choice |
| Social Capital Model | • strong focus on schools and children's centres as hubs of the community<br>• multi-purpose locations for children and young people, families, communities and professionals |
| Implementation Model | • clear implementation timetable now emerging<br>• detailed regulation and guidance pending<br>• localities undertaking anticipatory implementation |

# Section 3: Four Levels of Implementation

Implementation is multi-faceted. Different types of literature emphasise different aspects of the implementation process, but overall four levels can be identified (Box 5). All of these need to be addressed simultaneously.

**Box 5: New vision for adult care: Four levels of implementation**

1. Central government level
2. Locality strategic level
3. Community/neighbourhood level
4. Individual level

### 1. Central government level

There have been repeated calls in recent years for a more coherent approach to policy for adult care at central level. So far Wales is the only UK country with an overall vision and strategic policy framework for an ageing society. The NAO noted that despite some progress in joining up policy making, there remains a lack of coordination in some areas - an understandable difficulty given the 14 separate Government departments identified as having a stake in older people's issues alone. When other users of adult social care services are also included, the fragmentation of central government responsibilities becomes even more pronounced.

But although there is agreement on the need for a coherent policy framework at the centre, there is less agreement on how this can best be achieved. Given the socially inclusive service model identified earlier in this report, the Department of Health is only one of several key departments - indeed currently the Secretary of State for Work and Pensions is the Government Champion for Older People and DWP the designated lead Department. The relationship between a new vision developed by the Department of Health, the Link-Age model proposed by DWP and the work of the Social Exclusion Unit on adult social care service users needs to be clarified. More broadly, the extent to which the new vision will constitute a 'National Strategy for Adults' or a much more narrow 'Social Care Strategy' needs clarification. The view of the key stakeholders consulted in this paper is that it should be the former.

A joined-up central strategy needs to be matched by joined-up inspection and performance management. Several concerns are being currently expressed. First, there are concerns about the high volume of national targets and the risk that these become the focus of local activities and a substitute for proper business planning.

Secondly, targets tend to encourage and perpetuate service silos rather than whole system perspectives; indeed, the proportion of PSA targets relating to older people that cross two or more departments actually fell from a third to a quarter between 2000 and 2002. Much is expected of the revised Comprehensive Performance Assessment due in 2005, which will include assessment of improvements in strategic and corporate capacity to address cross-cutting issues in the hope that this will sharpen the focus of local authorities' relationships with other key organisations and with their communities. However, it is important that similar expectations are placed upon other statutory partners, especially the NHS. *Every Child Matters* outcomes will be performance managed through an integrated inspection process that brings together Ofsted, CSCI and the Audit Commission; it will be important for the 'adult inspectorates' to take a similar joint approach.

Finally, central government can play a vital role in supporting localities in achieving these difficult shifts in perspective and activity. Whilst a more focussed and joined-up approach to inspection and performance management will be helpful, many localities will also need support rather than sanctions. The recent evaluation of the Change Agent Team has emphasised the value of this 'support force' model, in terms of its capacity to work by invitation with local sites to tackle practical issues and address key implementation needs - a practical way of filling a gap in the implementation process that would otherwise have been very difficult to address.

### 2. Locality strategic level

Strategic planning at locality level for adult care is at best patchy and more typically non-existent. The ADSS/LGA says of support for older people:

> *There is no effective mechanism to coordinate commissioning ... the challenge is to find ways of commissioning universal services on a joined up community wide basis, and specialist services on a system wide joint agency basis*.

Even where local strategic planning mechanisms do exist, they are likely to focus on specific groups of adult social care service users, such as people with learning disabilities or mental health service users. The question of whether an overarching local strategic framework for all adult social care services is required needs to be addressed.

The NHS Plan proposes the use of joint or lead commissioning arrangements across health and social services, but other opportunities and policy levers to engage a broader range of partners also exist:

- under the Local Government Act 2000, councils have powers to produce a community strategy setting out how they intend to promote the economic, social and environmental wellbeing of their area;

- the 1999 Health Act allows local authorities and health bodies to pool resources, and local partners also have the option of establishing integrated care trusts;
- standard eight of the NSF for Older People (Promoting Health and Active Life) requires activity across the NHS, most of the local authority and many agencies in the voluntary sector;
- local health delivery plans have potential value, but have yet to exhibit a whole systems approach.

However, despite such initiatives and opportunities, there is still no consistent governance framework in which commissioning can operate across all needs and all partners, and this fragmentation has been exacerbated by the increasing number of partnerships instigated following central government directions. Many of those involved in local partnerships complain of partnership fatigue, increased bureaucracy and greater confusion among the public concerning how to access local services and who is providing them.

The logical answer to the whole systems strategic imperative is seen by some to lie in revitalised Local Strategic Partnerships (LSPs) - the only local vehicles with the remit to bring public sector organisations together with each other and with the private, business and community sectors to tackle issues that require coordinated action across a locality. Currently LSPs are variable in their effectiveness, not least because performance management approaches emphasise silo rather than whole systems approaches. An important proposal from ADSS/LGA is that LSPs should provide a local governance framework for older people; this could be extended to other client groupings. The establishment of Children and Young Person's Strategic Partnerships in each locality will be effectively mandatory and this could be matched by a similar Adult Persons Partnership Board. Such a Board would take overall responsibility for the commissioning process, with a group of staff drawn from the partner organisations preparing and implementing the commissioning strategy.

Notwithstanding the introduction of Joint Investment Plans in the late 1990s, very few localities seem to have developed coherent inter-agency and multi-sectoral strategies for their adult care groups, although there is much evidence of the development of focused partnerships built around delayed discharge and intermediate care. Further Government encouragement may be necessary to match current local requirements to produce a children and young person's plan. Wider use of the planning model already developed by the ODPM, DoH and the Housing Corporation would be useful here. This proposes a broad-based, whole systems planning framework based on five levels, ranging from citizenship and active ageing (Level 1) to hospital and long-stay residential and nursing home care (Level 5), thus allowing a full range of current services to be mapped for each level. It is possible to envisage a model of this kind also promoting more innovative use of locally available funds, such as pooling funding from social services and PCTs with money from the Supporting People programme to invest in preventive initiatives and services. The model can be applied at both local authority/PCT and neighbourhood levels, and used as a planning tool to change the future balance of services upstream. However it is currently seen as entirely optional.

With a strong and effective LSP and a range of appropriate Partnership Boards, it becomes possible to envisage a locality-based whole systems approach with the potential to address comprehensively the outcomes identified at the beginning of this report by making links across traditionally separate sectors and issues. Indeed, some localities have already taken important steps towards putting this into practice. The Sandwell Partnership has five thematic agendas (health/social care; community safety; environmental management; education; and access to employment). The West Norfolk Partnership covers six themes - the local economy; regeneration; crime and community safety; health; environment; and social inclusion. It is within such over-arching strategic partnerships that partnership boards for specific user groups can begin to relate to one another in more meaningful and ambitious ways that have the potential to address individual needs. Research for the Housing Corporation and Age Concern, for example, has shown that at locality level, older people have been marginalised from the regeneration process despite the fact that they are normally the most stable population group. Services are still generally planned in isolation rather than on a geographical basis, thereby missing out on the potential link into well-established community development approaches.

### 3. Neighbourhood/community level

There are two strands to this level - better integration of provider activity and the utilisation of social capital.

*Integrated provider activity*

Much of the focus of partnership energy over the past decade or so has been upon a range of inter-*agency* relationships, but the pressing need now is to also develop inter-*professional* working with a view to joining up provision. Developments or proposals are already underway in this regard. The Link-Age approach proposed by DWP, for example, aims to build on the experience of the Care Direct pilots in Southwest England in delivering easily accessible information to older people. Under the Link-Age blueprint, joint teams - Pension Service staff, social workers, social services staff responsible for financial assessments and possibly housing and council tax benefit staff will identify needs and eligibility in a single visit to a person’s home, with one professional taking the lead role - the Consultation Document talks of providing ‘a whole person service’. Although the proposal has not been received uncritically by the welfare rights lobby, it is nevertheless possible to extend this idea more broadly to other user groups.

An alternative model is the ‘Connected Care Centre’ aimed at people with complex needs and located in deprived neighbourhoods, which would provide all of the support services needed under one roof, thereby taking social care to those who require it most. Building on the Sure Start model, such Centres would combine health, mental health, disability and substance misuse services with support and advice about benefits, education, housing and employment. Turning Point suggests:

> *Someone walking through the door would enter a web of support that held them while they addressed the various problems they were tackling ... the Centre would become the heart of the community with people living there having a key role in determining how they developed and are run.*

Such a model would require ‘service navigators’ - a new kind of professional working in a service brokerage role to help people navigate their way around health, social care, housing and employment services. These navigators would have knowledge of all mainstream and specialist services and would work with the service user to develop a sustained pathway of care, as well as having an advocacy remit. It is not evident that individuals with such qualities are readily available, suggesting the need for an associated programme of workforce development.

In the meantime there is a range of statutory inter-professional arrangements in existence or being developed around the country that focus upon specific user groups (especially learning disability, mental health and intermediate care) or on geographical localities and staffed by fully integrated teams covering community health, social work, housing and support services. The ACCESS programme in Sedgefield is one example. It is likely that greater encouragement and support is required for such initiatives to become more widespread. In the meantime, the development of practice-led commissioning in the NHS creates an important opportunity to link primary and community health services with other neighbourhood-focused services, including social care, housing and other services, especially for people with long-term conditions. It is important that practice-led commissioning does not focus solely on GPs’ perceptions of their patients’ needs for specialist health services, but contributes to the development of a ‘whole person’ approach.

*Utilising social capital*

The contribution to social care made by family carers is well documented, with an estimate that the monetary value (in terms of foregone state expenditure) amounts to £57 billion. The task is often demanding, and carers themselves need support if they are to continue caring - the 2001 census shows that most carers are of working age, but one in six are older people themselves. Given such large numbers, formal support for carers is relatively limited. However, social changes, including changing family structures and obligations and the frailty of many older carers, may have a negative effect on traditional caring contributions.

While intensive and personal care may continue to be provided largely by family members, these trends have nevertheless led to renewed interest in other forms of social capital. People live their lives within webs of relationships that extend beyond the family to include neighbours, friends and people with whom they share common interests, and these relationships sustain self-identity and self-esteem. Despite the social trends identified above, recent projects with older people in Leeds and Hartlepool found strong values of mutuality and neighbourliness that survived losses in physical and social capital. Promoting and sustaining such networks requires interventions that can increase opportunities for fostering social exchange, particularly among people who may have little social capital on which to draw. Several approaches with an application across all adult care groups have been suggested:

- The *Communities that Care Programme* is adapted from a preventive programme developed in the USA aimed at children and young people. Strategies for building ‘healthy environments’ include physical fabric and the environment, the nature and accessibility of amenities (for leisure, socialising, health, fitness and so forth), and the quality of the socio-cultural environment. Service users are seen as part of the solution, not just as the source of problems.
- *Active Citizenship and Social Responsibility*. The DWP’s Link-Age consultation calls for a discussion on how the promotion of neighbourliness and community support can be encouraged, but concedes this will not be easy to achieve.
- *Optimisation and Compensation Models*. These approaches argue that in order to understand why some people cope with ageing and disability better than others, it is necessary both to acquire a qualitative understanding of the experiences of older people themselves, and to understand how socio-cultural factors (such as socio-economic situation, gender and ethnicity) intervene and impact on health and life chances. This approach can clearly be applied to other groups and situations. A preventive service could accordingly be seen as part of the range of resources that can be drawn upon to support processes of optimisation and compensation.
- *Social Rehabilitation Projects* aim to address the problems that arise from social isolation by using resources that go beyond social care services to help people remain integrated within their local community. Social rehabilitation projects run by Age Concern are time-limited (to 13 weeks) and aimed at restoring confidence and skills impaired through illness, injury, bereavement or other loss; they can be seen as more social- and community-oriented versions of intermediate care. Similar projects exist overseas, represented for example by the Greek ‘Open Care Centres’.
- *Time Banks* offer a model for recognising and rewarding family carers. In a time bank, participants earn time credits for helping each other - one hour of your time entitles to one hour of someone else’s time. Credits are deposited centrally in the time bank and withdrawn when help is needed; help is exchanged through a broker who links people up and keeps a record of transactions. Time credits have no monetary value, so are unlikely to affect carers’ benefit entitlements. A national network of over 100 time banks - Time Banks UK - is already in operation.

## 4. The individual level

There are two broad approaches at this level - enhanced professionally led implementation through care plans and pathways; and user led implementation through direct payments and similar schemes.

*Professionally led implementation: Care plans and pathways*

Care planning is of course not new, having been a major element of the community care reforms of the 1990s, but the process is now largely restricted to those on the cusp of institutional care. The ambition of improving support in the community for those with long-term conditions therefore needs to be accompanied by processes to identify potential problems and support people *before* a pattern of poor health has become established. In Denmark, for example, all people aged over 75 receive a visit twice a year from a municipal home care worker - additional visits may be made following a major crisis such as bereavement or hospital discharge. The aim of the visits is to identify and reduce risks such as falls and other accidents, social isolation, depression and physical inactivity. Older people are also given information so that, if such problems do arise, they are better prepared and more confident in dealing with them. Such a development could also be cost-effective - evidence from the use of care plans in asthma, for example, suggests that for every £1.60 spent on care plans, £7.00 is saved to the NHS, on top of improvements in quality of life and clinical outcomes. This implies extending care planning from a narrow social care remit to a multi-professional and multi-agency project that adopts a whole person approach and takes the outcomes identified at the beginning of this report as guides for action. Unless the care plan reflects users' own goals and sets out what a person could do to maximise their own quality of life, then the effects will be sub-optimal.

Very similar points can be made about the kindred concept of care pathways, which have traditionally been developed to describe the journey of a patient with a specific condition through a series of services. Care pathways can be a means of jointly agreeing an ideal service and identifying gaps in current services, or of ensuring that people move smoothly from one (part of the) service to another. However, they tend to be confined to only one part - typically the acute part - of a system and sometimes neglect to make vital connections when care transfers to other organisations and professions. The wider concept of process mapping could counteract this narrowness by mapping details of what happens when service users access health, social care and wider systems. By analysing detailed flows of individuals across the whole system, process mapping allows participants to identify bottlenecks, duplications and waste, as well as encouraging knowledgeable front-line workers to influence change.

These sorts of developments need a skilled and responsive workforce - without full recognition of the rights and needs of care workers, social policy cannot be implemented. One recent report concluded that there is a shortage of qualified social care staff, and competition with other sectors for unqualified staff. The position is exacerbated by national shortages in the NHS of GPs, community nurses and other professionals, and by the latters' relative lack of experience in working across agency and professional boundaries. Commissioning policies therefore need to take account of workforce development issues, including an understanding of small-scale local labour markets and the potential for linking local regeneration to vocational training initiatives. There are opportunities here for collaborative working across social care, health and the independent sector - locality-based whole systems workforce planning. This could include the alignment of job evaluation programmes - a vital task where the intention is to have different professional staff working side-by-side at the front line. The respective job evaluation schemes - *Agenda for Change* in the NHS and *Single Status* in local government - are a means of addressing this dilemma. However, currently the NHS scheme is moving ahead much faster than that in local government and the relationship between the two schemes is too loose to provide a joint framework for job evaluation.

*User led implementation: Direct payments*

Direct payments and other forms of 'consumer directed care' are rooted in demands for independent living - a movement that has consisted mainly of persons of working age. However, although 1.4 million adult social care packages were delivered in 2002/3, only 9,600 clients received direct payments. Some see this as a disappointing achievement; the analysis of responses to earlier consultation on a new vision for adult social care also noted the infrequency with which people identified direct payments, suggesting that '*professionals do not see them as a necessary tool for the personalisation of care'.*

For those who use direct payments, there is certainly evidence of benefits. One review of the experience of using direct payments noted that:

> *A significant feature has been how the quality of life of the disabled person has improved; the sense of feeling in control has been a central aspect in all the findings ... choice and flexibility were the other themes. The other significant point is cost-effectiveness compared with in-house direct service provision*.

One reason for the low take-up of direct payments is the weakness of what might be termed an enabling infrastructure. It has been suggested that to take full advantage of consumer-directed services, a number of preconditions have to be fulfilled:

- consumers need to have a sophisticated overview of potential suppliers;
- competition between providers is required to foster service differentiation;
- staff need training in user empowerment and providers need to develop more user-oriented services;
- service users need to be involved as much as possible in service design and development;

- cash allowances need to be combined with other tools for integrating care already identified in this report - direct payments are not so much a *substitute* for coordinated care as an alternative means of accessing it.

In addition, an expansion of direct payments has implications for local authorities' commissioning and market management roles, and may create tensions with the development of strategic, whole systems approaches to local service commissioning, since a rise in direct payments means that more people will purchase and manage the delivery of care themselves, rather than have it commissioned by statutory agencies.

However, direct payments are not the only model of using cash payments to empower service users. A recent international survey of schemes designed to offer adult care service users more choice and flexibility identifies three models:

*Personal budgets and consumer-directed employment of personal assistants*
This is the model that best describes the UK's direct payments scheme. It also includes the Dutch Personal Budget scheme where working age and older people eligible for social insurance benefits for long-term care can receive cash payments instead of services. Significantly, Personal Budgets can be used to purchase formal care and nursing services, or pay family members to provide support. A ceiling of €300 per day (the equivalent cost of nursing home care) is imposed, and income-related co-payments are also required. Nevertheless, Personal Budgets have been popular - the numbers opting for them increased from 5,400 in 1996 to 65,000 by 2003. However, budget holders experience difficulties finding help at a price they can afford and the system is administratively complex - at the end of the 1990s, some 30 per cent of allocated Personal Budgets remained unspent.

Some consumer-directed care programmes in the USA are variations on this approach. Programmes in Colorado, Michigan and Oregon, for example, offer consumer-directed support options as part of Medicaid personal care. These follow one of three models:

- direct pay, where the consumer is the employer with full hiring, firing and payroll responsibilities;
- fiscal intermediary, where a designated agency handles payroll and taxes and the user selects and manages the employee;
- supportive intermediary, where a public agency helps with matters like recruitment, criminal checks and training.

*Payments to the person needing care*
The person receiving the payment can then spend it as s/he likes but has to acquire sufficient care. Typical of this model is the German long-term care insurance scheme, again covering older and younger disabled people. The scheme offers a choice of benefits in the form of a (lower value) cash payment, in-kind services, or a

combination of both. The cash benefit has always been much more popular than services in kind - about 80 per cent of eligible beneficiaries opt for this - and it is assumed that in most cases this is passed on to the family carer and becomes part of the household income. However, the beneficiary and her/his family are responsible for securing sufficient care and the beneficiary's health and wellbeing are checked every three to six months; if s/he is thought to be receiving inadequate or insufficient care, then the cash allowance may be withdrawn and in-kind services substituted instead.

*Payments to care-givers as income support*
Such payments both compensate for the loss of wages and provide social acknowledgement of carers' role. However they are not meant to provide full compensation for the support provided; rather they sustain a minimum level of income for people unable to have a full-time job because of care responsibilities. The UK and the Irish Carers Allowance are examples of this approach. However, although this approach offers carers entitlements to income of their own, on its own does not increase choice or control for people needing support.

These approaches only work well with a well-developed and diverse supply side, as well as the provision of information from professional services and support from informal carers.

## Every Child Matters 'Read Across'

Finally, in this section, the opportunity is taken to 'read across' between the New Vision issues and the *Every Child Matters* proposals, shown in Box 6 below.

**Box 6: Levels of implementation: Adults and children and young people's services compared**

| Implementation Level | New Vision for Adult Care | Every Child Matters |
|---|---|---|
| Central Government Level | • cabinet committee for older people<br>• integrated inspection and performance management<br>• supportive 'change agent' model | • coordinating cabinet committee<br>• integrated inspection and performance management<br>• regional change advisers |
| Locality/Strategic Level | • revitalised LSPs<br>• strategic partnership boards<br>• cross-agency plans for adult care<br>• links with other mainstream domains in a locality | • revitalised LSPs<br>• children & young people's partnership boards<br>• cross agency children & young people's plans<br>• links with other mainstream service domains |
| Community/Neighbourhood Level | • single accessible information points<br>• integrated and responsive teams of professionals<br>• neighbourhood level commissioning<br>• maintenance and development of social capital | • community focal points: extended schools and children's centres<br>• co-located joint teams<br>• neighbourhood links/commissioning with schools<br>• the community as a source of social capital |
| Individual Level | • single assessment process<br>• information sharing systems<br>• enhanced care planning/care pathways<br>• process mapping<br>• matching workforce developments<br>• consumer-led commissioning | • common assessment framework<br>• information sharing systems<br>• lead professional<br>• multi-agency care planning<br>• matching workforce reform<br>• consumer-led commissioning through school choice |

It is evident from the outline comparisons at each stage of this report that the scope for compatibility between the possible new vision for adult care and the emerging changes to children's services is high. It is not clear how important such compatibility is at central level, but it would certainly make a great deal of sense at locality and neighbourhood level to maximise this synergy. Indeed, the earlier some such intention is made evident the better, for this would help to shape the way localities are handling the re-creation of organisational and professional relationships. It has not been possible in this report to go beyond the outline comparisons, but a fuller analysis could be undertaken if needed.

# Conclusion

This report has drawn on a range of recent literature and documents published by organisations of service users or reflecting very high levels of user consultation and involvement. It has identified three linked dimensions of a ‘New Vision for Adult Care’, each with several sub-components. The overall framework is shown in Box 7 below. It has not been easy to address the generic components of an ‘adult care’ model without sacrificing some of the special concerns of specific constituencies such as mental health, learning disability and drug and alcohol misuse. Nevertheless, we suggest that the contours we have identified will have a resonance across the whole field of ‘adult social care’ and beyond.

**Box 7: New vision for adult care: Overall framework**

| | |
|---|---|
| Ten User Outcomes | • maintaining independence<br>• keeping clean and comfortable<br>• clean and orderly environment<br>• being safe<br>• access to social contact and company<br>• keeping active and alert<br>• living healthier and longer lives<br>• an adequate income<br>• opportunities to contribute to the community<br>• feeling valued |
| Ten Service Principles | • a whole person model<br>• a whole systems model<br>• a comprehensive model<br>• a user empowerment model<br>• a reciprocal model<br>• a checks and balances model<br>• a personalised service model<br>• a choice and diversity model<br>• a social capital model<br>• an implementation model |

| | |
|---|---|
| Four Levels of Implementation | **Central**<br>• coordinated national policy<br>• integrated inspection and performance management<br>• national support force<br>**Local Strategic**<br>• revitalised LSPs and community plans<br>• strategic boards and plans for adult social care<br>• optimal links across services and sectors<br>**Neighbourhood/Community**<br>• single point of access<br>• integrated and co-located front line teams<br>• connected care centres<br>• sustain and develop social capital<br>**Individual Level**<br>• single assessment<br>• care planning/care pathways<br>• workforce reform<br>• direct payments |

The development and implementation of a ‘new vision’ for adult social care offers a unique opportunity to move away from provider-led services towards an approach that starts from the outcomes that service users aspire to. By drawing on reports and publications that reflect the views of service users, this report has sketched out the parameters of those aspirations. The active engagement of service users in the next steps of the ‘new vision’ will help to ensure those aspirations are achieved.

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# Appendix 2: Organisations Contacted and Responding

| **Organisation** | **Documents downloaded/received** |
|---|---|
| Action for Blind People | Y |
| ADFAM | Y |
| African-Carribean Organisation of the Blind | Y |
| Age Concern England | Y |
| Alcohol Anonymous | N |
| Alcohol Concern | N |
| Alzheimer's Society | Y |
| Anchor Housing | Y |
| ARMA (Arthritis and Musculoskeletal Alliance) | Y |
| Arthritis Care | N |
| ASBAH | N |
| Asian Disability Network | No website |
| Asian People with Disabilities Alliance (APDA) | N |
| Asian People with Disabilities Network (AND) | N |
| Black Disabled People's Association | N |
| Brain and Spine Foundation | N |
| British Council of Organisations of Disabled People | Y |
| British Deaf Association | Y |
| British Heart Foundation | N |
| British Limbless Ex-Service Men's Assoc (BLESMA) | Y |
| British Polio Fellowship | N |
| Brittle Bone Society | N |
| Cancer BACUP | N |
| Care Directions | Y |
| Carers UK | Y |
| Chinese Mental Health Assoc | Y |
| Cocaine Anonymous | N |
| Combat Stress | N |
| Community Care | Y |
| Contact the Elderly | N |
| Counsel and Care | N |
| Crossroads – Caring for Carers | Y |
| Cued Speech Association UK | N |
| Deafblind UK | N |
| Deafplus | Y |
| Deafplus | Y |
| Demos | Y |
| Depression Alliance | Y |

| | |
|---|---|
| DIAL UK | N |
| Disability Information | Y |
| Disabled Living Foundation | N |
| Disabled Parents Network | Y |
| Down’s Heart Group | N |
| Down’s Syndrome Association | N |
| DrugScope | Y |
| Epilepsy Action | Y |
| Family Service Units | Y |
| Family Welfare Association | N |
| Family Welfare Association | N |
| GLAD (Greater London Action on Disability) | Y |
| Haemophilia Society | Y |
| Headlines | N |
| Headway | N |
| Headway | N |
| Hearing Concern | N |
| Help the Aged | Y |
| Huntington’s Disease Association | N |
| Incapacity Action | N |
| Independent Living Alternatives | N |
| IPPR | Y |
| JRF | Y |
| Limbless Association | N |
| Living Options | N |
| Long-term Medical Conditions Alliance | Y |
| Mencap | Y |
| Mental Health Foundation | Y |
| Mind | Y |
| Motor Neurone Disease Association | Y |
| MS Society of Great Britain | Y |
| Narcotics Anonymous | N |
| National AIDS Trust | Y |
| National Autistic Society | N |
| National Centre for Independent Living | Y |
| National Centre for Independent Living | Y |
| National Federation of the Blind | N |
| National League of the Blind and Disabled | N |
| National Society for Epilepsy | N |
| NCVO | Y |
| No. 10 Strategy Unit | Y |
| Office of the Deputy Prime Minister | Y |

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|---|---|
| Pain Society | Y |
| Paradigm | Y |
| Parkinson’s Disease Society of the UK | N |
| Partially Sighted Society | N |
| Psychiatric Rehabilitation Association | N |
| Real Life Options | N |
| Refugee Action | Y |
| Release | N |
| Re-Solv | Y |
| RETHINK | Y |
| RNIB | N |
| RNID | Y |
| Royal Association for Deaf People | Y |
| SANE | N |
| Schizophrenia Association of Great Britain | N |
| Scope | Y |
| Shaping Our Lives | Y |
| Social Care Institute for Excellence | Y |
| Social Market Foundation | N |
| Tackling Drugs | Y |
| Terrence Higgins Trust Lighthouse | Y |
| Thalassaemia Society UK | N |
| The Disabilities Trust | Y |
| The Foundation for People with Learning Disabilities | Y |
| The Mental Health Foundation | Y |
| The Stroke Association | N |
| Turning Point | Y |
| UKHCA | Y |
| Values into Action | N |
| Women’s Aid Federation England | Y |
| Women’s Alcohol Centre | N |
| Women’s Health | N |