PUTTING PEOPLE FIRST and SUPPORTING CARERS

SOME KEY MESSAGES for LOCAL LEADERSHIPS

Contents

* Note: since this paper was first prepared, ADASS together with the Department of Health and the Local Government Association has published *"Putting People First, Transforming Adult Social Care – progress measures for the delivery of transforming adult social care services* [September 2009]

Note: Unless stated otherwise in this paper, terms such as "people" and "individuals" embrace carers and service users.

FOREWORD

There can be no doubt that over the coming years the need for leadership will be stronger than ever. Councillors and Directors must ensure that they provide leadership to improve the quality of life of carers. The demands on carers arising from the recession will require greater support and this must be delivered more flexibly and more responsively.

This short paper highlights the role of Councillors and Directors in providing leadership :-

> ➢ In creating effective partnerships
> ➢ In making sure carers benefit from personalised services
> ➢ In shaping their local area with the LAA/LSP to ensure accessible services for carers
> ➢ In developing and sharing learning on what works for carers

ADASS is committed to providing leadership at a national level to improve outcomes for carers and this document is our contribution to strengthening leadership at a local level.

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Introduction

1.   Policy Background

1.1   This is a time of enormous change. The national agenda seeks to respond to a range of social, demographic and economic pressures that are driving reform within health and social care. This has been a momentous period with publication of five key documents all of which are relevant to carers:

> ❑ Putting People First: a shared vision and commitment to the transformation of adult social care, December 2007 [1]
> ❑ Carers at the heart of 21st –century families and communities, June 2008 [2]
> ❑ High Quality Care for All: NHS Next stage review final report June 2008 [3]
> ❑ NHS next stage review: our vision for primary and community care, July 2008 [4]
> ❑ Transforming the quality of dementia care with consultation on and subsequent publication of a national dementia strategy [5]

1.3   Publication reflects Department of Health priorities for social care for carers and people who use services. These are:

> ❑ Commissioning for outcomes
> ❑ Delivering the dementia strategy
> ❑ Personalisation of services
> ❑ Early intervention and prevention
> ❑ Dignity and respect

1.2   For ease of reference, summary information on **Putting People First** and **"Carers at the heart of 21st – century families and communities"**, the new national strategy for carers is set out in Appendix A.

2   Focus of this Paper

2.1   In May 2008 the Princess Royal Trust for Carers and Crossroads Caring for Carers organised a roundtable event called **"Putting People First without Putting Carers Second".** The products of the day were set out in a short paper with the same title [6].

2.2   The roundtable write-up identified some 25 projects covering a wide range of activities. There was also a discussion around issues arising from individual and local experience. The paper concluded with a series of action/discussion points. These are around:

> ❑ The interdependence that often exists between the service user and the person cared for and the need for services to reflect this.
> ❑ The value in approaching assessment and personalisation using a person centred care model that appropriately balances and builds upon social network support for both service users and carers.
> ❑ The value of information and advocacy in ensuring choice and control and in promoting independence and well being for service users and carers

2.2   This short paper draws on material from the roundtable event. It seeks to identify some messages that may help Councils, consistent with their leadership role under **Putting People First**, and their partners within the NHS and third sector to translate this shared vision around personalisation as it applies to carers and the people they support. There are three broad themes:

       ❑   Partnerships and performance
       ❑   Personalisation and carers
       ❑   Pilots, sharing and learning

2.3   It is hoped that, by sharing and using local experience in this way, we can test relevance to some of the main messages about system reform: quality of experience, evidence based, sustaining independence and well being, people being treated fairly and equally, personalised care and support with choice and control.

Messages for Local Leaderships

3   Partnerships & Performance

3.1   The majority of the examples from the roundtable event involve some form of operational partnership arrangement. Very few involved an organisation working on its own. This may reflect the composition of those taking part in the roundtable event. Equally, it could reflect a pattern of partnership working that has developed and the vital contribution local networks can make to effective service provision.

3.2   What does come across is a picture of schemes that have a clear focus and have a local system capacity building element within them. How their achievements are measured is less clear. The event points to a continuing need to find realistic ways of doing so. The examples have a fit with other evidence [7] around what makes partnerships work.

3.3   One message is that a clear focus on outcomes, which is supported by sound partnership structures and processes, tend to work better than those where this is not the case. These are areas that are best clarified at project initiation stage and tested through periodic evaluation and feedback. Both, however, require data and this was a focus for debate during the roundtable event. Without intelligent information, however, improving performance on support of carers may be difficult.

3.4   Directors of Adult Social Services and Children's Services together with Directors of Public Health have a role here in making three links:

       ❑   Contribution to local joint needs assessments [JSNA] [8]
       ❑   Coherent local joint priorities in response to wider local needs [9]
       ❑   Delivery of meaningful and measurable outcomes against needs.

3.5   Making such links and identifying outcomes requires data and information sharing. Carers receiving assessments and support [NI 135] forms part of the core data set for services. Estimated numbers of carers, however, do not form part of the demographic assessment within the JSNA core dataset. We would encourage discussion about this at local level in terms of expected numbers of carers within a given population. In doing so, there are three tools have been developed by beacons in association with Carers UK, ADASS and CSCI [10], currently subject to review along with *"Care to take a look"* [11]. All are available for local use to help review local performance and delivery against an overall strategic approach.

3.6   Without these data, and more importantly an overall strategic approach, it is difficult to assess gaps or how far local services really match with local needs. The roundtable event suggests there may be benefits, nationally and locally, about the information and evidence requirements that would advance local responsiveness to carers both strategically and operationally. In this way we can respond to concerns about the burden of information collection and better ensure that a more evidence based approach leads to improvement.

3.7 There is a helpful IDeA briefing on including carers in Local Area Agreements [12] Recent information on Local Area Agreements suggests a significant number include national indicators on Direct Payments/Individual Budgets [NI 130] and/or Carers receiving assessments and support [NI 135]. Of the two, however, use of NI 130 [direct payments/individual budgets] is less frequent. Not all agreements include these national indicators. It is accepted there remain concerns around the adequacy of the carer indicator NI 135. They are being examined.

3.8 Whilst this use of indicators is to be welcomed, all local partnerships should still consider whether carers needs have been identified sufficiently and linked to the four themes within LAAs around delivery of national and local priorities. Use of the "beacon" toolkits, for example, might be considered as a mechanism for raising awareness across partnerships and in discussion of priorities for improvement consistent with the outcomes set out in the new national strategy for carers.

3.9 The roundtable material was arranged around impacts or outcomes for carers and the person cared for. This was a helpful approach but the contribution of all projects needs to be framed in a more strategic commissioning context. CSCI consulted recently on its Performance Assessment Framework for 2008/09. A number of organisations have made suggestions for a strengthened carers dimension for national performance assessment consistent with the status of the new national strategy. This is to be welcomed.

3.10 If accepted, there may be local requirements for data. The real benefits of this approach may need to be communicated and explored further. This is because we need to balance national initiatives of this kind and the burdens they may involve with the need for development of local mechanisms for assessing need strategically, responding in partnership to areas for improvement and ownership of shared local priorities for change and delivery.

3.11 The recent report by the Lifting the Burdens Taskforce, "**Review of Health and Social Care Burdens"** [13] considered performance management data collection. The paper confirmed that local authorities recognise the importance of good quality information to understand, demonstrate and improve social care outcomes. There is a commitment to work with government to this end. Where there are concerns they are about duplication, meaningfulness and utility in relation to improving service delivery. These are not new issues but the current change agenda, not just for carers, requires a sharp focus on their resolution at an early date.

3.12 There is general acceptance that more systematic and comparable national information on carer experience [not satisfaction] has a value. Individual experiences are capable of aggregation but capturing them is not always easy. More work is needed and intended in this area. It may be that model data collection formats, available for use on a toolkit basis at local level, could offer a way forward. There may also be a case for a limited national survey mechanism.

3.13 Whatever approach is adopted in moving forward we must be able to demonstrate what action has been taken in response to what has been said in carer and service user experience surveys whether they are local or national. This is critical to the credibility and delivery of meaningful change for carers and those they support.

4.   Personalisation & Carers

4.1 **Putting People First** is clear that *"… real change will only be achieved through the participation of users and carers at every stage"*. The roundtable event in May 2008 reinforced that message. It looked at personalisation and how carers are part of that agenda in the same way as service users are.

4.2   The focus of personalisation is improving people's lives and overall quality of life There is a close relationship between the health and well being of the carer and the person cared for. Both will have needs and they may not always be the same.

4.3   One of the messages from the material is that offering real choice and putting people in control of their services and support requires a mutuality of understanding, real organisational cultural shifts, strong communication, support and leadership.   This becomes more essential as we move from pilot to mainstreamed personalised care and support.

4.4   Almost inevitably, there is a risk that improvements in one area may, unless there is a systems and family wide view, have unintended consequences or result in unmet needs in another. The roundtable discussions identified some examples of this and the concerns voiced are real. The roundtable event recognised there may be a creative tension between personalisation for the user and recognition and support for the carer. Whilst needs may be inter–related, they are not always the same. Individual assessments need to recognise both.

4.5   The Brighton and Hove example given around learning disabilities from the roundtable event is useful. This outlines ways forward in resolving potential tensions in ways so as to ensure personalisation delivers for users and carers in a way that is respectful of the rights of both parties. This is a timely reminder that change requires support and monitoring to keep it on track and evaluation to make sure it delivers what it should.

4.6   Equally important is the emphasis placed by the roundtable event on a wider quality of life approach, not just for carers but for service users as well. The value and importance of holistic and cross agency approaches in promoting inclusion, improved health, independence and well being, for example, has been identified within *Sure Start* [14] and *Opportunity Age* [15] and some councils [16].

4.7   The development of such models can be helpful in linking local action to strategic context and outcomes for carers. A draft quality of life model for carers has been produced as part of the preparation of this short paper. It appears as **Diagram One.** The Princess Royal Trust for Carers and Crossroads Caring for Carers have developed a carers' support model. This is linked to the key outcomes within the national strategy. Both models offer real opportunities to think about how we can make sure carers benefit from accessible and personalised services.

5.   Learning & Leading

5.1   Pilots are an important mechanism to test out new ways of working. A number of high impact and partnership ventures have been described. They are a selection from the day. We are sure there are many more. This, for us, remains one key issue: how can be better identify and share evidence based best practice that can be used across care and support services to improve quality, encourage innovation, offer a basis for evidence based action and share learning?

5.2   The new national strategy places some emphasis on pilots and allocates resources for this purpose. These pilots will be accompanied by arrangements for evaluation. Whilst local evaluation is important, there is also a need for consistency across the programme if common themes and issues from pilots are to be identified and assessed at national level.

5.3   Accessible information to promote sharing of learning is relevant here. As well as the invaluable resources offered by carer organisations there are three web sites where information on practice and development can be found. They are:

- ❑ IDeA Knowledge www.idea.gov/idk/aio   www.beacons.idea.gov.uk/idk/aio
- ❑ SCIE – www.scie.org.uk/
- ❑ CSIP - www.csip.org.uk/

5.4   In addition, carer networks and the regional arrangements for carer leads to meet and share information offer valuable opportunities to exchange ideas and learning. Much of this information, however, is not captured systematically or is lost. There is a case, therefore, for developing further the existing mechanisms for tracking carer initiatives and identifying good practice and learning. Web sites, for example, once established need to be maintained. This includes the adding new information, in standard form, on new ventures as well as updating information and contacts on material already recorded. People will then use them.

5.5   In March 2008 the Care Services Improvement Partnership [CSIP] [17] published a paper on a series of organisational initiatives which were seen as changing health and social care services and the lives of people who use them. There are some strong parallels between that work and the content of the roundtable day. There appears to be significant common ground when it comes to implementation. There are, perhaps, three main messages from both pieces of work:

- ❑ Put service users and carers at the centre of service design and planning
- ❑ Recognise change is complex, needs leadership and systematic review
- ❑ Ensure staff are skilled in and embrace new ways of working.

5.6   More recently, the Cabinet Office Social Exclusion Task Force has published *"Think Research"* [18]. This looks at how we can best use research evidence to inform service development for vulnerable groups. It recognises the shared commitment, nationally and locally, to improve the use of evidence to inform service commissioning. It sees evidence informed choices with improved outcomes for people firmly at the centre. The paper reinforces messages around evaluation. These are that evaluation should:

- ❑ Be integral to projects and not an afterthought;
- ❑ Involve all relevant stakeholders [includes carers and users]
- ❑ Act as a trigger for learning, whether positive or negative; and,
- ❑ Be a catalyst for implementation.

6.   Moving Forward

6.1   The commissioning context for the roundtable day was an operational one and project specific. A latent but important question is the need to link partnership and innovative pilots back to their strategic context: what are the overall needs within the community and how do the projects contribute to delivery of the outcomes the new national strategy for carers wants to see by 2018.

6.2   *Joint Strategic Needs Assessments* will be a critical mechanism for ensuring that the role of carers is recognised on both the demand and supply side of any need – supply - demand forecasting activity. This includes:

- ❑ Population profiling/prevalence
- ❑ Anticipating future needs and preferences
- ❑ Service user and carer profiling
- ❑ Analysis of met but unsatisfied demand.

6.3 Strengthening understanding of the strategic context within which services and support are developed can only be helpful in demonstrating relevance and links to outcomes. Further work in this area testing, for example, the utility of models such as the IPC framework for joint commissioning and purchasing of public care services [19] may be helpful.

6.4 Another area for exploration is how we can better manage issues around scaling and scope for replication of pilots and other innovative work. One of the challenges facing many pilots is subsequent mainstreaming and affordability. This is not just about sustainability of innovation and commitment of those involved. It also involves turning the new into established organisational working whilst retaining the creativity of the pilot period. New ways of doing things by staff may be involved. This may lead to issues around workforce planning and organisational development. These need to develop in advance of change or at the same time rather than afterwards.

6.5 The change process may extend to a review and development of information systems used for service delivery and budgetary control to ensure systems work for people and not the other way around. It also involves active and continuous engagement with carers and users so the significance and impacts of change is understood. The practice guidance on the Carers and Disabled Children Act, 2000, [20] continues to be a valuable resource for the development of multi-agency approaches to help provide carers with a life outside caring.

6.6 The *Commissioning Framework for Health and Well Being* Guidance [9] offered a number of helpful suggestions about giving local people voice and choice. The Darzi principles [fair, personalised, effective, safe and locally accountable] are equally relevant to care and support for carers as are the principles of *World Class Commissioning.*

6.7 The *Operating Framework for 2008/09* [21] included carers for the first time. The NHS in England Operating Framework for 2009/10 is expected to reflect the national strategy commitments for carers around personalisation, recognition, family friendly practice and care pathways. In line with the commitments in the national strategy it will cover the £150M funding for *pilots for breaks*.

6.8 Local Involvement Networks and Overview and Scrutiny Committees have a potentially key role here in promoting creative and responsive action around additional PCT funding for breaks. There should also be examination around how we can make better connections with expert patients and carers' programmes such as *"Caring with Confidence"* and initiatives flowing from the national strategy supported by new Department of Health funding through Primary Care Trusts.

6.9 A further issue is the proportionate strengthening, standardising and simplifying of data collection arrangements around carers to provide for benchmarking and learning. There is a need to be able to demonstrate the added value flowing from data collection activity and to show how it informs the process of continuous performance improvement around outcomes locally.

6.10 Lastly, we return to the issue of how we can better share learning and knowledge about work with carers and develop models to underpin action. There is considerable knowledge around the country and dissemination of intelligent information around what works [or does not] can only be helpful. Improving and supporting internet access to such information can only be beneficial and further debate is needed. Everyone has a responsibility to use these, and to build and learn from their experience in doing so.
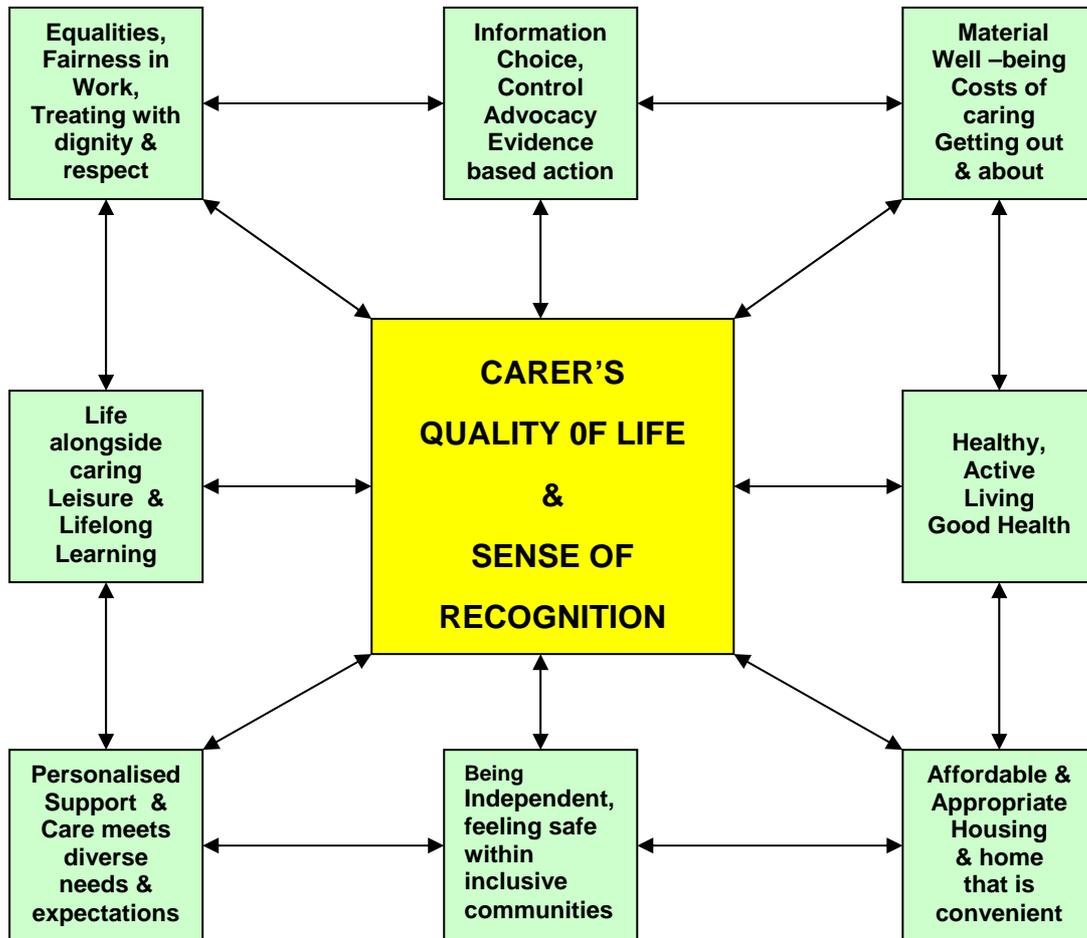
7   Summary: Five High Impact Areas

7.1   In summary, there are five high impact areas flowing from the IPC commissioning model [19] that local leaderships and commissioners might consider in the coming months. They are:

- ❑ **Plan:** Ensure joint strategic needs assessments inform joint strategies on carers and delivery priorities within the local area agreement.
- ❑ **Partner:** all agencies work together to ensure active involvement of carers as partners about priorities and delivery, experience and outcomes.
- ❑ **Procure:** joint and operational commissioning frameworks driven by needs and expectations of carers and service users.
- ❑ **Personalise:** strategic and operational commissioning promotes personalisation, individual budgets, direct payments and self-commissioning.
- ❑ **Product:** carer experience and outcomes for carers match needs, expectations and intentions of commissioners and inform the future.

7.2   The development of Joint Strategic Needs Assessments and inclusion of carers issues within Local Area Agreements and place shaping strategies all offer real opportunities to strengthen local strategic commissioning frameworks for carers and generate a better sense of voice, value, and veracity in the delivery of accessible and personalised services. Put in very simple terms, the high impact areas are all about *"doing what it says on the tin";* having made sure first, of course, it is the right tin, at the right price, with the right contents and is being used for the right purpose.

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DIAGRAM ONE

A QUALITY OF LIFE MODEL FOR CARERS
[For Discussion]

Equalities, Fairness in Work, Treating with dignity & respect	**Information Choice, Control Advocacy Evidence based action**	**Material Well –being Costs of caring Getting out & about**
Life alongside caring Leisure & Lifelong Learning	**CARER'S QUALITY 0F LIFE & SENSE OF RECOGNITION**	**Healthy, Active Living Good Health**
Personalised Support & Care meets diverse needs & expectations	**Being Independent, feeling safe within inclusive communities**	**Affordable & Appropriate Housing & home that is convenient**

Source: Adapted from: The Future is Ours [16], A Sure Start to Later Life [14] & Opportunity Age [15]

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APPENDIX A

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CARERS AND PERSONALISATION

NATIONAL POLICY BACKGROUND

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1.   Policy Background

1.1   The 2006 White Paper*, Our Health, Our Care, Our Say* [22] outlined the Government's intention to achieve four main goals:

- Provide better prevention services and earlier intervention
- Give people more choice and a louder voice
- Do more on tackling inequalities, social exclusion and improving access to community services
- Give more support for people with long-term needs.

1.2   At national level the reform agenda continues. The 2007 Budget and Comprehensive Spending Review outlined the imperatives of adult social care reform. These reflect the need to respond to the challenges of demographic change, rising expectations and the increased emphasis on user and carer choice, voice and control. All are linked to the principle of care closer to home and whenever possible and practicable support for independent living within the community consistent with the seven key outcomes for social care listed below:
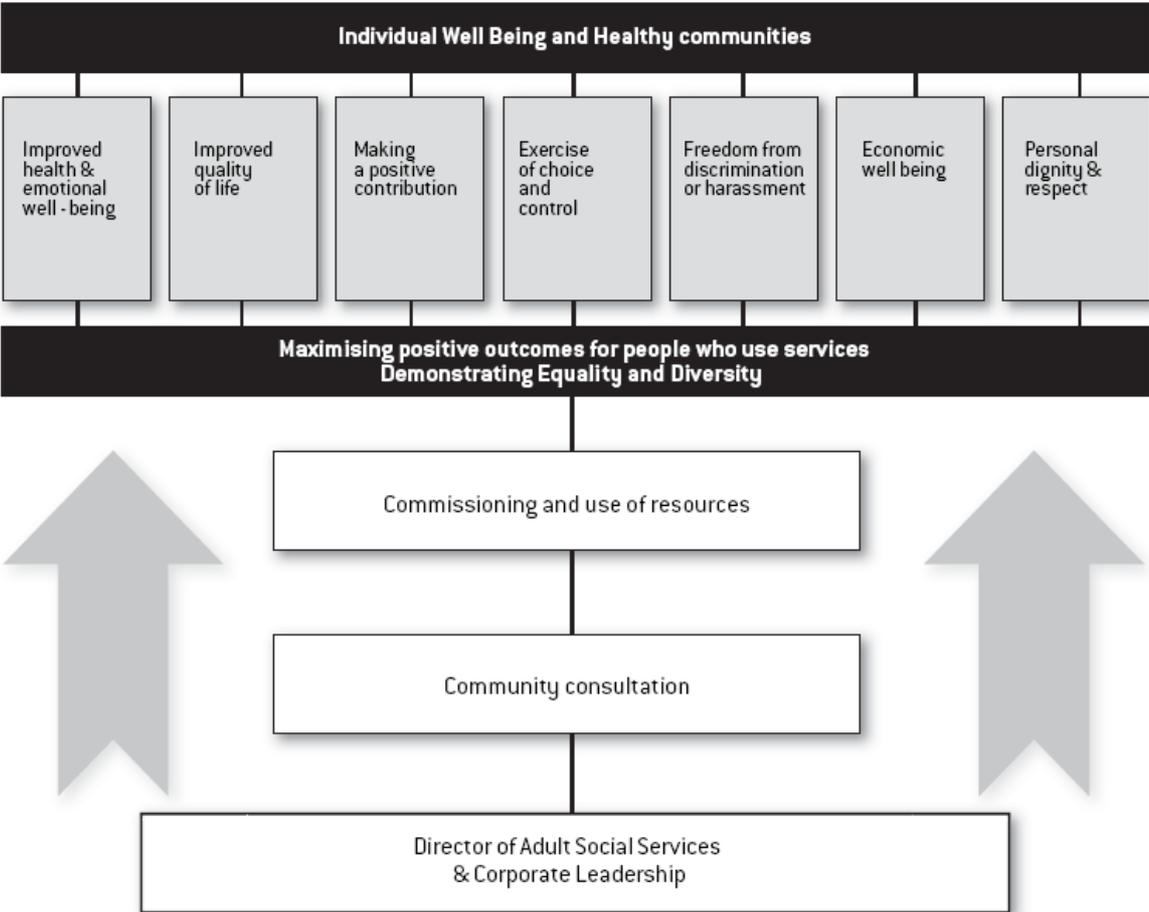
2   Putting People First

2.1   The Department of Health wants to see transformational change within social care over the next three years. The aim is to deliver support tailored to individuals and local populations irrespective of their circumstances and levels of need. Personalisation and early intervention are seen as key issues for the whole of local government and not just for adult social services.

2.2   On 10 December 2007 *Putting People First* the first concordat [1] signed by adult social care and health providers across all sectors, the NHS Executive, central and local government, professional bodies and regulations was published. Key elements included:

- ❑ Giving most people who receive funded care their own personal budgets
- ❑ Much closer collaboration between NHS and local government
- ❑ A focus on early intervention and prevention
- ❑ Investing in support that tackles loneliness and isolation; and,
- ❑ Joint strategic needs assessments undertaken by councils, PCT and NHS providers

2.3   Central to the reformed system is local authority leadership and partnership working with the local NHS, other statutory agencies, independent sector organisations, users, carers and the wider community. The expectation is that there will be shared outcomes designed to ensure that, irrespective of illness or disability, people are able to:

- ❑ Live independently
- ❑ Stay healthy, recover quickly from illness
- ❑ Exercise the maximum control over their own lives
- ❑ Sustain family units and age appropriate caring roles
- ❑ Participate as active and equal citizens
- ❑ Have the best possible quality of life
- ❑ Retain maximum dignity and respect.

2.4   The social care reform process is being supported by Social Care Reform Grant [23]. This has to be used for process re-engineering, capability and capacity building activities and includes work to:

- ❑ Move from traditional service provision focussed on inputs and processes towards more flexible and efficient ways of working that focus on outcomes people want and need and promotes their independence, well-being and dignity.
- ❑ Generate a shift from a culture of crisis intervention towards more early intervention focused on independence and well being in line with needs of the local population.
- ❑ Engage people more in the design, commissioning, evaluation of service and how their needs are met; ensuring choice and control in every setting at every stage.
- ❑ Remodel systems and processes so they are more efficient and equitable and recognise the ability of individuals to identify cost effective personalised solutions.
- ❑ Join up services to provide easy to recognise access points with no wrong front doors and an ability to connect with hard to reach people.
- ❑ Raise the skills of the workforce and promote new ways of working and new types of worker along with cultural change to deliver new ways or working
- ❑ Generate leadership at all levels of local government and communities to support change.

2.5   Councils are expected to develop monitoring plans and delivery arrangements. These are expected to be consistent with the analysis flowing from the local Joint Strategic Needs Assessment. Councils are also expected to work with regional consortia and improvement agencies and to start progressing local action for service transformation. This includes engaging with other partners, service users and carers, user led organisations. Action is then expected to find expression in Local Area Agreements [LAAs].

2.6 In practice this means that by 2011 all councils will be expected to have made significant steps towards redesign and reshaping of their adult social care services, having regard to their joint strategic needs assessments. The key components expected to be in place include:

- Everyone eligible for statutory support should have a personal budget, a clear and transparent allocation of resources, with many more people having the opportunity to take all or part of this budget as a direct payment.

- A strategic balance, based on local needs, between enablement, early intervention and prevention and provision for intensive care support for those with high-level complex need.

- A common assessment framework across health and social care to deliver a more diverse range of local services and solutions, with greater use of self-assessment, supported decision making and appropriate safeguarding arrangements.

- Robust arrangements to ensure that the views and experiences of users, carers, user led organisations and other stakeholders are central to every aspect of the reform programme.

- A market development and stimulation strategy with evidence of action to deliver change and meet local needs.

- A workforce with the capacity, capability and culture, across all sectors, needed to deliver choice and support control; with staff who are trained and empowered to work with people to enable them to manage risks and resources.

2.6 Success will be monitored through improved outcome based indicators, the Care Quality Commissions performance assessment process and under the new arrangements for comprehensive performance assessment [CAA].

3. National Carers Strategy

3.1 HM Government launched its National Strategy for Carers on 10 June 2008. Called *"Carers at the heart of 21st century families and communities: A caring system on your side. A life of your own"*, it sets out a series of initiatives and some new commitments to help and improve the lives of carers. It gives a framework for a ten-year programme and a vision of what the Government wants to see in place for carers by 2018. It replaces the 1999 strategy *"Caring about Carers"*. The strategy covers the United Kingdom and is a cross government initiative endorsed by the Prime Minister and seven Secretaries of State. Health and social care aspects are specific to England.

3.2 The vision is that by 2018 *"… carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen"*. The key outcomes the Government is seeking are:

- carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;
- carers will be able to have a life of their own alongside their caring role;
- carers will be supported so that they are not forced into financial hardship by their caring role;
- carers will be supported to stay mentally and physically well and treated with dignity;

❑ children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the **Every Child Matters** [24] outcomes.

3.3 The government sees its role as being made up of four elements:

❑ providing leadership
❑ monitoring implementation
❑ setting the overall objectives
❑ helping to join up services

3.4 The strategy also outlines the role of families and wider society; including employers. Delivery of the new national strategy and its vision will be pursued through:

❑ progression of existing commitments [e.g. National Helpline and Expert Carers];
❑ short term new commitments, starting this year, and lasting until 2011; and,
❑ longer term identified priorities between 2011-18.

3.5 Resource provision is identified for the short-term commitments. The areas for action and further consideration are linked to each of the five strategic outcomes for carers.

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* **Note:** since this paper was first prepared, ADASS together with the Department of Health and the Local Government Association has published *"Putting People First, Transforming Adult Social Care – progress measures for the delivery of transforming adult social care services* [September 2009]

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[9]   **Department of Health**, *"Commissioning Framework for Health and Well-being",* DH, March 2007.

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        Balanced scorecard – strategies
        Questionnaire for carer feedback

        Available: www.beacons.idea.gov.uk

*Note: subject to updating and review in October 2008

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* Note: Since this paper was prepared, the Government's national strategy *"**Living well with dementia: a National Dementia Strategy"*** was published on 3 February 2009.

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