Leave Behind

'Caring for our future' Engagement

Desk Research to Help Inform the Approach

14 October 2011

Contents

1.0 Introduction

- The Department of Health (DH) is progressing policy ideas to inform a White Paper on Social Care reform and a progress report on funding that are due to be published in Spring 2012

- A programme of engagement, *Caring for our future*, launched on 15 September 2011 and will feed into the White Paper

- The purpose of this document is to help inform the approach for the *Caring for our future* engagement. It pulls together what is already known in relation to the defined priority themes for the engagement and identifies gaps in knowledge and understanding

- This was a pragmatic exercise conducted in a short timescale and this document is intended to inform discussion about the focus for further engagement

- The content is presented in succinct note style for easy reference.

- The priority engagement themes that have been included in this exercise are:
    - Personalisation
    - Prevention and early intervention
    - Quality and workforce
    - Integration
    - The social care market

- We have omitted the role of financial services from this research exercise. The policy questions in these financial workstreams were complex and broad ranging, and largely relate to the recently published recommendations of the Commission on Funding of Care and Support. For these reasons, desk research would be unlikely to uncover anything of direct relevance

1.1 Objectives

- The broad objective of the desk research review was to succinctly summarise what is known about both stakeholders' and the general public's views in relation to the defined question areas in the engagement concerning social care reform. In so doing we sought to identify current gaps in knowledge and understanding

1.2 About the desk research review

- 82 sources (market research and engagement reports) were consulted, dating predominantly from 2008 onwards, and drawn from:
    - COI archive
    - The source listing in the Commission on Funding of Care and Support literature review (Ipsos MORI, 'Public opinion research on social care funding', February 2011)

- The sources do not include academic research sources

- The document has been structured according to the relevant content found. In some cases, this has been by types of stakeholder, but in other cases by themes that emerged

1.3   Weighting of sources

- The sources were largely qualitative and included a number of reports from large-scale engagement events. Within the scope of these methodologies, all sources included are considered robust

- Where practicable, we have indicated where opinions have come from across a range of sources. Beyond this, given the nature of this desk research exercise, it would not be appropriate to attempt to ascribe relative importance against particular points

2.0   Overarching themes

Across the sources and policy issues, three overarching themes emerged, which touched on all of the policy areas to some degree:

- **Information provision** – clear, accessible and timely information is required by service users and other audiences in order, for example, to support personalisation and service integration

- **Involvement** – choice and control is key to the personalisation policy and a core component of quality adult social care for service users, carers and their families

- **Workforce** – the quality, skills set and training of the adult social care workforce is one of the cornerstones of service quality, joined-up working, personalisation, the health and well-being of service users and the future of the adult social care market

3.0   Personalisation

Three questions areas were explored:

- What can be done to put people in greater control of their care/support arrangements?

- Priority areas to support greater personalisation?

- Key barriers to personalisation and how to address them, including attitudes amongst the workforce?

Overview

Overall, personalisation was mentioned within numerous research sources to varying degrees

We mainly garnered perspectives from users, families and carers. There is limited coverage of stakeholders' views

The question area which received comparatively greater coverage was 'key barriers to personalisation' while 'priority areas to support personalisation' received the least coverage

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3.1   What can be done to put people in greater control of their care/support arrangements?

Users' perspective

- Involve service users and carers in the design of social care services and allow participation in the decision making process[1]

- Individuals with learning disabilities will require significant levels of support throughout their lives, for example personal care, eating, day to day tasks; older people and disabled people could be supported to live independently[2]

- Considerable support anticipated to be needed with (inevitable) bureaucracy likely to be associated with personalisation – already some struggle with form filling[3]

- Better financial advice – make it an integral part of the long-term care system. Care users and experts in the care communities have already identified the lack of information and advice as a serious problem. This should be achieved by compelling local authorities to signpost people to regulated financial advisors, once they have conducted a needs assessment[4]

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[1] Ref 50, 76 (Sample: General Public)
[2] Ref 17 (Older people, disabled people and people with learning difficulties)
[3] Ref 17 (Older people, disabled people and people with learning difficulties)
[4] Ref 73 Policy Exchange paper

- Remaining in own home where possible is seen as crucial and everything should be done to make this happen[5]

Stakeholders' perspective

- Stakeholders wanted to ensure that people are enabled to be active contributors to their care and support rather than passive recipients, but still have adequate support in place - aiming for interdependence rather than independence[6]

Family and carers' perspective

- Reassure family and carers that they can have a say during the assessment process and that their wishes would also be taken into account[7]

- The idea of supporting individuals to stay at home resonated with many, particularly amongst ethnic minority audiences[8]

- There is a call for greater information provision for carers, more financial and emotional support. Also for carers to receive training to allow them to provide services safely[9]

3.2   What are the priority areas to support greater personalisation?

- Ease of understanding the social care system (from the users, families and carers perspectives) seemed to be an issue that will be important and hence a priority[10]

- A member of the public succinctly summed up the issue: "(It is) essential for the Government…to create a system which is easier to navigate, responds to needs and which secures dignity and choice"[11]

- As personalisation is a key underpinning principle of the social care system one research source suggested that it would be "a waste not to publicise this potential public opinion winner"[12]

- Personalisation was seen to be particularly important for those with fluctuating care needs. Mental health problems were cited as an example of where care needs can vary greatly over time, and there was a concern that a National Care Service take account of those whose needs are episodic[13]

- Remaining in own home where possible seen as crucial, and everything should be done to make this happen[14]

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[5] Ref 17 (Older people, disabled people and people with learning difficulties)

[6] Ref 27 (General public/Stakeholders)

[7] Ref 7 (General public/Ethnic Minorities)

[8] Ref 7 (General public/Ethnic Minorities)

[9] Ref 7 (General public/Ethnic Minorities)

[10] Ref 9 (General public)

[11] Ref 39 (General public)

[12] Ref 10 (General public)

[13] Ref 23 (General public/Stakeholders)

[14] Ref 17 (Older people, disabled people and people with learning difficulties)

3.3   Key barriers to personalisation

- The idea of personalised care and support and the emphasis on choice is welcome, although there is concern that there may not be sufficient funding to make it a reality[15]

- Stakeholders suggest that personalising care and support requires a different care workforce as professionals might be asked to offer new services or adopt different ways of working to deliver the care and support people really want. Some note that there should be an emphasis on social workers and volunteers as well as more traditional carers, and sufficient support must be provided for these groups [16]

- Training is an issue. There is not enough training to cater for the needs of the individual. For instance in meal preparation, some people are only trained in how to make porridge, but some users don't want porridge[17]

- People with dementia – it was suggested that there should be as much effort made as possible to have the same carer for the same person. It does not do the dementia sufferer any good to have a different stranger in their house[18]

- Social care staff suggest there are signs that the infrastructure to support the growth of the workforce is lacking – issues around boundaries, financial arrangements, training and support require resolution. Many of these require consideration about how to develop and support a safe and proficient workforce. Growth of the workforce without this, risks creating both a vulnerable workforce and vulnerable employers[19]

- Directors of Adult Social Services express their acceptance and enthusiasm for personalisation, they feel equipped to be able to implement this change. Some however, are aware that there are pressures and contradictions that the Personalisation agenda raises with regards to budgets[20]

- Personalisation is likely to see a growth in the number of Personal Assistants, and being able to communicate with the workforce effectively, including this audience segment, will become important. There is a need to understand how receptive this audience is to communications about their role and the social care sector and to uncover some of the challenges that may lie ahead in being able to cascade key messages about reform and policy.[21]

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[15] Ref 50 (General public)
[16] Ref 23 (General public/Stakeholders)
[17] Ref 76 (General public)
[18] Ref 76 (General public)
[19] Ref 4 (Social Care staff)
[20] Ref 4 (Stakeholders)
[21] Ref 4 (Stakeholders)

4.0   Prevention and early intervention

Four questions areas were explored:

- Definition of prevention and greater prevention and early intervention

- What are the priorities for supporting prevention and early intervention?

- Changing culture and behaviours amongst individuals, families and communities

- Better integration of health and social services around prevention and early intervention

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Overview

Overall there were both gaps and limited coverage (within the research reports) on the specific policy question areas. Where information was identified it tended to be quite broad, lacking in adequate depth to provide much in the way of insight into attitudes in this area

Prevention efforts in the form of fall prevention programmes and help around the house received coverage

More broadly, however, the principle of tailoring prevention to the user rather than imposing a one-size-fits-all approach was advocated

One research report focussed on a number of initiatives to support carers

Areas where information gaps exist include: how to better integrate health/social services and also changing culture/behaviours amongst individuals, families and communities

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4.1   Definition of prevention and greater prevention and early intervention

- It isn't clear what 'prevention' includes, and who would provide prevention services. Suggestions that a greater awareness of care and support services is needed, and education could be key to prevention[22]

- 'Prevention services' needs to be broadly defined to include 'low-level' support in the community, sometimes provided by volunteers and not just traditional home care.[23]

- The term 'early intervention' was perceived as plain and lacking warmth[24]

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[22] Ref 23 (General public/stakeholders)
[23] Ref 23 (General public/Stakeholders)
[24] Ref 17 (Older people, disabled people and people with learning difficulties)

4.2   What are the priorities for supporting greater prevention and early intervention?

• Interventions that provide information services, help around the house, fall prevention, physical activities should be the focus of prevention efforts[25]

• Fall prevention programmes, decreasing (not eliminating) risk of falling - a fall is the most common cause of injury among the elderly, and injury is a leading cause of death and long-term disability in this group.[26]

• Prevention must consider users' needs and, like other elements of the proposed service, should not be a 'one size fits all' approach. For example, keeping people active is seen to be a core aspect of Prevention, yet for some illnesses, rest rather than activity at an early stage could be vital.[27]

• Generally the research pointed to supporting full time carers for whom caring often has physical and emotional detriments. Specific examples of support included:
    – Flexible appointments systems at GPs that prioritises carers – realisation that there are two patients.
    – Providing planned breaks is a priority, to relieve physical and emotional impact of caring, enabling carers to have a life outside caring
    – Improving access to employment and training opportunities
    – Healthcare professionals to be more proactive in identifying respite needs and offering services where appropriate; make sure users are aware of respite facilities.
    – Identifying young carers as soon as possible so as to receive support as soon as possible.[28]

4.3   Changing culture and behaviours amongst individuals, families and communities

• Few respondents, according to one research study, wish to contemplate a future 'in care', their misconceptions ("They'll put me in a home") often prevent them from seeking early low level assistance that could keep them independent for longer.[29]

• Living independently is perceived positively. That the Government is encouraging older and disabled people to be more in control of their lives, and to live in their own homes for as long as possible is welcomed, since it means less reliance on others. A minority of participants however interpret this as the Government avoiding its responsibilities by encouraging people to live independently. Indeed, there is some cynicism here – an underlying feeling that this is a tactic adopted by the Government in order to distance itself from people in need of care, leaving people to deal with their problems alone.[30]

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[25] Ref 73 (Policy Exchange)
[26] Ref 73 (Policy Exchange)
[27] Ref 23 (General public)
[28] Ref 15 (Adult and young carers, people who are cared for, General public and professionals involved in implementing policy)
[29] Ref 10 (Users, potential users, and providers of social care - informal and formal)
[30] Ref 28 (Seldom heard citizens)

4.4 Better integration of health and social services around prevention and early intervention

- Involving carers in all stages of care provision requires urgent attention - health professionals do not take into account their expertise and circumstances when designing appropriate care services.[31]

- There ought to be increased training for healthcare professionals and there would be benefits to working more collaboratively and systematically.[32]

- There should be a greater emphasis on health checks at certain ages and the promotion of healthy lifestyles.[33]

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[31] Ref 15 (Adult and young carers, people who are cared for, general public and professionals involved in implementing policy)
[32] Ref 15(Adult and young carers, people who are cared for, general public and professionals involved in implementing policy)
[33] Ref 23 (General public/stakeholders)

5.0   Integration

Six question areas were explored:

- How can we take advantage of the Health and Social Care modernisation programme to ensure services are better integrated around people's needs?

- Better service integration within the NHS, between the NHS and local government services (including examples of good practice)

- Benefits and purpose of integration, i.e. better health and care outcomes, better care experience, better value

- Barriers to/incentives for better integration

- Innovation in integrated care

- How to measure success?

Overview

Coverage of barriers and incentives to better integration is reasonably good, and includes the views of service users, service providers and other stakeholders

Coverage of better service integration within the NHS, and between the NHS and local services, and examples of good practice, is limited, and weighted towards stakeholders. The question area on benefits and purpose of integration is also limited.

Sources generally pre-date the set-up of NHS Future Forum and current changes underway, although earlier insights may still apply, and are included here

There is little coverage of innovation and how to measure success.

Context

- In 2008, unprompted awareness of integration as a key government policy was low: 1% among social carers, 7% among occupational therapists, 5% among social workers[34]

- Stakeholders feel the boundary between health and social care is unclear[35]

- Informal carers identify a lack of service co-ordination centred on carers' needs. Greater cohesion is required to bring greater personalisation[36]

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[34] Ref 16 (Social workers, social carers)
[35] Ref 23 (General public/stakeholders)
[36] Ref 15 (Adult and young carers, people who are cared for, general public and professionals involved in implementing policy)

5.1 Better service integration within the NHS, between the NHS and local government services

Informal carers' perspective[37]

- Service co-ordination to ensure person cared for receives the most timely interventions in a format tailored to personal needs

- Adult carers want employers to be more flexible, and support wanted in their journey back to work

- All carers want priority GP visits and appointments for both self and person cared for, and medical and emotional support

- Young carers want more understanding and support from school/staff, and for all services to identify them as early as possible

- Joined-up information to ensure information flows smoothly between departments and bureaucracy is kept to a minimum

- Claims process to be improved by reduction in number and complexity of forms

- More effective data sharing is key – professional to professional, professional to carer

Service users' perspective

- For those with learning disabilities, a way of finding meaningful activity once courses are exhausted is a critical issue[38]

Providers' perspective[39]

- For drug and alcohol abuse, service provider links into housing, education and other key support organisations and networks

- Older people need support of partner services – district nurses, GPs, speciality nurses – in order for excellent service to be delivered

Wider stakeholders' perspective[40]

- Stakeholders particularly focused on the need for health and social care working more closely together and sharing objectives, and stressed the role of the third sector in helping to co-ordinate what happens at the local level. Stronger relationships between public, private and third sector are also crucial

- Need for greater collaboration in housing, pensions, leisure, education, transport, planning, employers, criminal justice and community networks

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[37] Ref 15 15 (Adult and young carers, people who are cared for general public and professionals involved in implementing policy)
[38] Ref 17 (Older people, disabled people and people with learning difficulties)
[39] Ref 1 (Stakeholders, including providers of residential and domiciliary care)
[40] Ref 26 (Stakeholders)

- Need for closer day to day working between frontline workers, especially health and social care

- Need for a stronger understanding of *who* is responsible for *what*

- Health care should be included within an integrated service along with housing, young people moving from children's to adults' services, and end of life services[41]

- Stakeholders observe the need for continued improvements in joint working between different parts of the care and support system (and health services), so that users are not passed between different agencies.[42]

Examples of good practice[43]

- Program of All-Inclusive Care for the Elderly (US PACE) able to offer highly personalised care, effective clinical co-ordination and continuity, resulting in decreases in hospital and institutional admissions and cumulative days used, all of which positively impacted on Medicare costs

- Vittorio Veneto and Roverto (Italy): improvements on several functional measures for individuals receiving integrated care compared to control groups. Cumulative number of days older people spend in institutional care were reduced

- Integrated health and social care teams to support older people and vulnerable adults (Salford): improved access to and delivery of services. Co-location and proximity helped generate transfer of knowledge and development of shared practice to deliver more appropriate interventions for service users

5.2   Benefits and purpose of integration

Stakeholders' perspective

- Helping people to remain independent by the inclusion of wider services such as housing, education and leisure facilities in the prevention strategy – and by using other resources such as volunteers[44]

- Potential impact on obesity and early diagnosis of dementia through working more pro-actively with health sector, focusing on prevention and early intervention[45]

- Integrated approach crucial to reablement planning, requiring partnership working with: health services *(PCTs, GPs, nurses, Rapid Response Teams)*, service providers, housing services, and third sector organisations *(to exploit extensive information resources, e.g. on ethnic minority issues)*[46]

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[41] Ref 23 (General public/stakeholders)

[42] Ref 27 (General public/stakeholders)

[43] Ref 83 (DH desk review of integration of health and social care services)

[44] Ref 23 (General public/stakeholders)

[45] Ref 23 (General public/stakeholders)

[46] Ref 22 (Stakeholders)

- Reduction in duplication, with a quicker transition between referrals and services[47]

- Improvements in joint working and better information and guidance for users and their families will help to ensure a 'person-centred' approach'[48]

General public's perspective

- Simple accessible information for informal carers outlining all they needed to know – especially for disability where a number of agencies (NHS, local authorities) are involved[49]

Departments of Health review on integration between health and social care services[50]

- Emerging evidence of improving access to care, managing demand and reducing delayed transfers (Ham and de Silva, 2009)

- Some evidence that integrating health and social care delivery can lead to early intervention, and so substitution away from acute care

- Evidence that integrated care teams can release savings – in particular, to support people with complex needs and can help delay events requiring health, social care and criminal justice intervention

- It is the assumption that integration allows patient journeys to be simplified, improves efficiency, and helps organisations meet the growing demand for health and social care services

5.3   Barriers to/incentives for better integration

Approach to funding / commissioning

- Stakeholders point to the different funding mechanisms for health and social care: *"Too many initiatives are undermined by the separate funding streams of PCTs and local authorities, and the need or desire of both parties to be involved."[51]* Pooled budgets for health and social care, particularly for preventative measures, are suggested

- Service users feel there is a false divide between social care and health care, perpetuated by conflicting funding arrangements[52]

- Some stakeholder organisations suggest that joint funding and commissioning, and development of common objectives, will solve current problems of conflicting objectives in, for example, the hospital discharge process[53]

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[47] Ref 23 (General public/stakeholders)
[48] Ref 26 (Stakeholders)
[49] Ref 42 (General public)
[50] Ref 83 (DH desk review of integration of health and social care services)
[51] Ref 23 (General public/stakeholders)
[52] Ref 65 (General public/social care users)
[53] Ref 26 (Stakeholders)

No short-term return on investment

- It has been indicated that integration 'costs before it pays', and lack of resources makes the move towards integration harder[54]

Cultural differences[55]

- Changing to complex multi-agency working is challenging due to the different cultures of different service providers – and different eligibility criteria; larger organisations, particularly, are noted as unused to joint working

- Perceived lack of understanding and communication between health and care services is a major barrier

- Having the same management leading a new system would be ineffective

- Changing culture and mindsets will be much more difficult to achieve than is perceived

Regional variation[56]

- National organisations observed a regional variation in integration, and some see the need for national direction as crucial, with local authorities planning and implementing the joined-up approach

Data protection[57]

- Stakeholders see compatibility and data protection issues as a barrier to joining up IT systems – an essential for integrated working

- Data protection is a concern for the general public – either not passing on information in a timely manner or passing on too much personal information; and *not* passing on vital information for fear of breaching the Data Protection Act is a concern for stakeholders

Bureaucracy

- Stakeholders consider bureaucracy to be a barrier to integration in many areas *(e.g. legislative, political, number of managers, assessment processes)*[58]

Incentives[59]

- Government should focus on breaking down barriers by providing clear messages and sharing good practice. Health and well-being boards and a national outcomes framework could potentially mobilise integration

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[54] Ref 83 (DH review of integration of health and social care services)
[55] Ref 23 – (Stakeholders)
[56] Ref 23 (General public/stakeholders)
[57] Ref 23 (General public/stakeholders)
[58] Ref 23 (General public/stakeholders)
[59] Ref 83 (DH review of integration of health and social care services)

- Significant reform to the GP contract may be needed to embed new incentives for integrated care

5.4   Innovation in integrated care

- Various pilot schemes are underway: for example, a new model for delivering care for older people, involving a collaboration between GPs, public sector organisations and third sector services, to provide a single point of access to an integrated community team (Bournemouth and Poole Teaching PCT)[60]

- Stakeholders suggest a new approach to data management, and more education about data governance; they also suggest that assistive technology could provide better care[61]

5.5   How to measure success?

- A national outcomes framework, focusing on outcomes rather than processes – bearing in mind that measuring the effectiveness of various integration projects against outcomes is not easy, or that integration may 'cost before it pays'[62]

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[60] Ref 83 (DH review of integration of health and social care services)

[61] Ref 26 (Stakeholders

[62] Ref 83 (DH review of integration of health and social care services)

6.0   Quality and supporting the workforce

Five question areas were explored:
- Definition of quality
- Factors that will improve quality
- National versus local approach to quality
- Factors that will develop the future workforce
- Mechanisms for raising concerns about quality

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Overview

Coverage is high in the area of defining quality in adult social care, with formal definitions from government and organisations, and informal definitions from the general public, informal carers, service providers and stakeholders

Coverage of national versus local approach to quality is also good, with a consensus across audiences

Differing perspectives emerge on what factors will improve quality and develop the future workforce, although coverage is good on both these areas

Gaps in coverage exist in the question areas of mechanisms for raising concerns about quality (from a service user's perspective), and who should be responsible for driving continuous quality improvement

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6.1   Defining quality in adult social care

Two 'formal' definitions of quality/excellence:

- Social Care Institute for Excellence (SCIE)[63]

  - A working definition of excellence in adult social care based on five sources of knowledge *(organisations, practitioners, policy community, research, and people using services and carers)* and bench tested among (predominantly) service providers[64]
  - design principles: 'service users are at the heart of everything an excellent service does'; an excellent service is informative *(useful, accessible, trustworthy information)*, outcome focused *(outcomes for and identified by service users, their carers and families)*, and evidence based *(views of service users, observations of services in practice)*
  - an excellent service enables users to have **voice and control** *(over significant life decisions, day to day choices, how things are run; and where choice constrained, it listens, explains, explores alternatives)*, **good relationships** *(with partners, family, friends and others; with staff – dignity and respect, warmth, empathy, kindness, choice and control; staff know people well*

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[63] Ref 1A (CQC, SCIE definition of excellence)
[64] Ref 1 (Stakeholders)

enough to personalise support) and **spending time purposefully and meaningfully** *(engage in activities and roles which bring pleasure and meaning, and enhance quality of life)*

- **organisational and service factors** that sustain excellent outcomes are culture *(leadership, values, policies, people, systems, quality assurance)* and continuous improvement and sustainable use of resources

- Commission for Social Care Inspection (CSCI)[65]

  - Eight Key Qualities established: 1. Real choice and support in making decisions 2. Services that can respond flexibly to individual circumstances 3. Proactive provision of accessible information with support to understand it 4. Ability to experience the same opportunities and risks as everyone else 5. Being heard and shown respect 6. Fairness and non-discrimination 7. The right to expect value for money from services 8. Freedom from fear, bullying, abuse, neglect

'Informal' definitions of quality:

Service users' perspective

- Good service progress – being valued and respected, 'good fit' with life choices/preferences, choice and control over services; quality of life – broadly, physical health and social relationships for patients, and greater focus on psychiatric symptoms for providers[66]

- Perceptions of what characterises quality vary across type of service (e.g. home care, residential care) and type of service user (e.g. mental health service users, carers or family members, older people)[67]

- Service users and providers emphasised that information provision affects the quality of care[68]

- Older people, those with disabilities or learning difficulties prioritised being treated as individuals – being respected about how they wanted to live their lives[69]

General public's perspective

- Hard to reach members of general public primarily see care in terms of staff quality - well-trained and highly qualified staff[70]

- Being treated with respect and dignity, having a choice and feeling involved in decision-making; local control and accountability are also part of quality social care[71]

- Continuity of care, and carer familiarity with the local community are cited as components of quality[72]

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[65] Reference in ref 67 (Disabled people)

[66] Ref 4 (Social care staff)

[67] Ref 82 (Service users, general public, stakeholders)

[68] Ref 8 (Stakeholders – directors and comms specialists)

[69] Ref 9 (General public)

[70] Ref 7 (General public/Ethnic minorities)

[71] Ref 30 (General public)

Stakeholders' perspective

- Stakeholders see quality as: focusing on the needs and aspirations of the individual, the involvement of the individual in the design of their care package, and a personalised package; empowering people to make choices and to have maximum control of their lives; transparency and information; and fairness, equality and consistency should be the underpinning principles[73]

Examples of best practice from providers[74]
- *Choice and control*
  - Care plan as starting point for evidence of excellence
  - On-site daily logs and feedback from carers
  - Internal user surveys – formal, informal
  - Service user group – monthly meeting without manager
- *Good relationships*
  - Access to SKYPE, ease of visiting (open door policy), telephones adapted to all needs
  - Staff surveys
  - How the service deals with complaints from users and families
  - 'My Home Life', a resource to help organisations achieve outcomes
- *Spending time purposefully and enjoyably*
  - Creation of a men's fitness club 'Slimming without Women', in response to residents' requests
  - Enabling residents to do things they like, such as gardening or rearing chicks to hens
  - Engaging specialist organisations such as the National Association for Providers of Activities for Older People (NAPA) and the Eden Alternative, dedicated to alleviating boredom and isolation
- *Service and organisational factors*
  - Investors in People
  - '360 Forward' tools that help leadership and offer a framework for relationships across staff, service users and families

Examples of best practice in user involvement in specifying service quality
- Older service users involved in defining quality specifications for home and residential care (Raynes, 1998; Raynes et al, 2001)
- People with learning difficulties living in residential care involved in specifying measures of staff job performance (Hatton et al, 2005)
- People with mental health problems involved in developing outcome measures for use in assessing outcomes of services (Lelliott et al, 2001)

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[72] Ref 23 (General public/Stakeholders)
[73] Ref 23 (General public/Stakeholders)
[74] Ref 1 (Stakeholders)

6.2　Factors that will improve quality

Better information provision

- Informal carers and young carers[75] want access to digestible information tailored to their needs, and a dedicated website. Young carers want enhanced access to information and guidance

- Service users, potential service users, and providers of social care (formal and informal)[76] feel that the role and provision of information is vital

- The general public[77] want to have clear, comprehensive information on services they can access

- Stakeholders seek the development of a range of communications tools for engaging the public – supported by government and delivered by local authorities. The tools would include, for example, clarification of reablement, and a clear guide to the cost of care[78]

- Directors and communications specialists in social care want DH to improve – but not extend – the presentation and delivery of existing material, typically related to up-to-date summarised material and advance warning of changes[79]

Greater clarity and efficiency of processes

- For service users, those with disabilities or learning difficulties, and older people, clarity and efficiency of the assessment ('means testing') processes are required[80]

- Older people, carers, and others with experience of the social care system want a simpler system in which entitlements are clearer[81]

- Stakeholders request clarity of eligibility criteria for reablement[82]

- Informal carers, including young carers, want reduced delays in assessments and provision of services[83]

- Service users and providers tend to see the system as adversarial and identify a need for advocates. Many of those in most need of care (and their carers) do not feel capable of navigating the processes[84]

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[75] Ref 15 (Adult and young carers, people who are cared for, general public, stakeholders)
[76] Ref 10A (Users, potential users, service providers)
[77] Ref 42 (General public)
[78] Ref 22 (Stakeholders)
[79] Ref 8 (Stakeholders – Directors and comms specialists)
[80] Ref 17 (Older people, disabled people and people with learning difficulties)
[81] Ref 34 (General public/stakeholders)
[82] Ref 22 (Stakeholders)
[83] Ref 15 (Adult and young carers, people who are cared for, general public, stakeholders)
[84] Ref 10A (Users, potential users and providers)

Greater involvement of users and carers in the design of services

- Stakeholders prioritise the involvement of service users and carers in the design of services[85]

- The general public feel that older people and their families should have control over the services they obtain, with the help of some level of state support[86]

- Service users and providers (formal, informal) suggest regular reviews of the chosen care package, as user needs evolve or change[87]

A more substantive commitment to social inclusion

- Those with a learning disability want to find meaningful activity when college courses are exhausted. This is a critical issue and there is no sense that a 'plan' for this group exists[88]

- Disabled service users want training and employment for disabled people of working age[89]

- Informal carers want flexible working and training to help them return to work[90]

Attraction and retention of quality staff

- Quality staff means being well-trained, accredited, regulated;[91] committed, understanding service users and getting to know them as people;[92] friendly, cheerful, nice, kind, caring, good sense of humour, trustworthy, makes service user feel valued[93]

Providers indicated specific factors that would improve quality across the different sectors and type of care:[94]

- *Domiciliary care:* 'enablement contracts', individuals-driven service provision

- *Older people:* observation and communication, the support of partner services, choice and control in discharge from hospital to residential care

- *Older people with dementia:* in-depth training for staff and families, an intensive and individualised approach, and re-integration into the community

- *Drug and alcohol abuse:* linking in to support networks that include housing and education, including users in the management of services

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[85] Ref 23 (General public/stakeholders)

[86] Ref 27 (General public/stakeholders)

[87] Ref 10A(Users, potential users and providers)

[88] Ref 17(Older people, disabled people and people with learning difficulties)

[89] Ref 27 (General public/stakeholders)

[90] Ref 15(Adult and young carers, people who are cared for, general public, stakeholders)

[91] Ref 1(Stakeholders)

[92] Ref 17 (Older people, disabled people and people with learning difficulties)

[93] Ref 81 (General public/stakeholders, Wales)

[94] Ref 1 (Stakeholders)

Informal carers forcefully recommended the following improvements:[95]

- Advocacy/a single point of contact; increased respite care/a minimum level of respite care for all/a dedicated local authority respite service; priority GP appointments (for self and the person cared for)

- Young Carers want support for the whole family, including access to a greater number and range of activities; provision of support in emergencies; funding for young carers' projects; and to work more collaboratively with full-time carers

General public, on behalf of informal carers

- Emotional support and training for the role of informal carer were also factors cited by the general public[96] that would improve quality, as well as an overall commitment to support informal carers[97]

6.3   Factors that will develop the future workforce

Stakeholders' perspective

- Government should increase providers' and stakeholders' awareness of policy areas, other than personalisation

- Guidance is needed on how to deliver excellence in austere times

- The workforce may need to develop a different set of skills to meet future needs and to take the sector forward

- The existing goodwill of workforce should be harnessed, and their role as potentially powerful advocates for the sector exploited, in order to help recruit quality staff[98]

- DH could consider how to sustain the growing workforce of Personal Assistants with the support it needs without losing valued flexibility and autonomy[99]

- Incentives such as the Care Quality Commission Excellence Award may provide a tangible judgement for users to make informed choices, as well as giving services a competitive edge, which in turn attracts commissioners[100]

- Address cultural issues within the care and support sector, including enabling the greater empowerment of users, and making training available for both formal and informal carers[101]

- Need for workforce development and capacity building to ensure local authorities can deliver free personal care services on schedule[102]

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[95] Ref 15(Adult and young carers, people who are cared for, general public, stakeholders)
[96] Ref 42 (General public)
[97] Ref 27 (General public/stakeholders)
[98] Ref 1 (Stakeholders)
[99] Ref 37 (General public)
[100] Ref 1 (Stakeholders)
[101] Ref 26 (Stakeholders)
[102] Ref 22 (Stakeholders)

Staff's perspective

- Request clear communication of policy areas to the workforce so that it may engage with the issues[103]

Informal carers' perspective

- Informal carers feel it is important for professional carers and others to have a greater understanding of the role of informal carers, and young carers need greater support and advocacy[104]

General public's perspective

- Staff quality and training is integral to implementing the vision for social care[105]

6.4   Barriers and challenges to improving quality and developing the workforce

- The general public already sees the care and support system as overstretched, with care facilities closing down and care workers unable to meet all their clients' requests,[106] and point to the challenge of attracting and retaining high quality individuals into a low paid profession[107]

- Service users feel that resources will be stretched if controls over claimants are not effectively enforced[108]

- Stakeholder organisations point to high turnover of staff and lack of training and regulation[109], and the totally inadequate levels of support for unpaid carers[110]

- Service providers indicated that the regulatory process – or 'burden of compliance' – combined with finite resources, was a barrier to delivering an excellent service. They also saw the growth in Personal Assistants as the current big challenge: local authorities might promote Personal Assistants as a cheaper alternative to other forms of care, which may carry the risk of introducing unapproved and unqualified carers into the market place. Service providers questioned whether this represented *real choice* for the service user.[111]

- A large-scale public and stakeholder consultation, and research among harder to reach audiences,[112] concluded that different cultures across different service providers can be a barrier to joined-up working, and that issues around data protection can undermine quality of service.

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[103] Ref 4 (Social care staff0

[104] Ref 15 (Adult and young carers, people who are cared for, general public, stakeholders)

[105] Ref 42 (General public)

[106] Ref 11 (General public)

[107] Ref 7 ('Unengaged' general public)

[108] Ref 17 (Older people, people with disabilities and people with learning difficulties)

[109] Ref 23 (General public/stakeholders)

[110] Ref 34 (General public/stakeholders)

[111] Ref 1 (Stakeholders)

[112] Ref 50 (General public)

6.5   National versus local approach to quality

Across several sources, the consensus across social care audiences is for a national approach to quality, although allowing for a degree of local flexibility

- On balance, the general public, stakeholders and service users tended to opt for national consistency, although argued that some local flexibility would be important to ensure the system delivers high quality, tailored services[113]

- While service users are less focused on national policies and more interested in outputs, the only negatives tended to relate to what were perceived as deficiencies in the delivery of local services, and issues in supplying correct facilities at the local level. It can be a postcode lottery with regard to access to services[114]

- Stakeholders favour national consistency over local flexibility, though some degree of local planning and budget control was required, and ring-fencing of local budgets was widely supported.[115] National assessment was viewed positively in terms of maintaining consistency: there was a need to remove the postcode lottery, where different local eligibility criteria and levels of access to services exist[116]

- Hard to reach members of the general public felt that ensuring national consistency was an essential priority, and equated with fairness. A national system of funding allocation, providing sufficient resource for a basic standard of care, which would then be supplemented locally, would be one way of addressing current inconsistencies[117]

Clear standards and definitions required at a national level to support consistency of quality:

- Informal carers support the establishment of national standards of care, underpinned by national guidance and monitored by an independent inspectorate[118]

- Service users seek a clear baseline entitlement, using nationally agreed eligibility criteria[119]

- Stakeholders require a consistent assessment tool, with a link between personal care at home and other related assessment processes, in particular, the NHS's Continuing Care and Single Assessment Process (SAP); they also require a definition of Activities of Daily Living (ADL) for free personal care *(clarifying the meaning of 'significant difficulty', and 'critical' versus 'substantial' need)* [120]

- The general public suggest a minimum training standard for informal carers[121]

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[113] Ref 50 (General public)
[114] Ref 17 (Older people, people with disabilities and people with learning difficulties)
[115] Ref 26 (Stakeholders)
[116] Ref 23 (General public/stakeholders)
[117] Ref 27 (General public/stakeholders)
[118] Ref 15(Adult and young carers, people who are cared for, general public, stakeholders)
[119] Ref 34 (General public/stakeholders)
[120] Ref 22 (Stakeholders)
[121] Ref 42 (General public)

6.6   Mechanisms for raising concerns about quality

Information on mechanisms for monitoring (and measuring) quality more in evidence than mechanisms for raising concerns about quality among service users:

- The Care Quality Commission (CQC) Excellence Award, the National Institute for Health and Clinical Excellence (NICE), and local council quality schemes all offer mechanisms for monitoring quality – although providers and other stakeholders question how they fit in with each other, and which will have the greater 'value'[122]

- 'Reporting Performance Information to Citizens' details the way in which local authorities report performance information *(Policy Research Institute, 2008, on behalf of DCLG)[123]*

- OFSTED was suggested as a model for frequency of assessment by one service provider[124]

- On a more informal basis, 70% of social workers claim to see a manager daily to discuss day to day issues[125]; and hard to reach members of the public suggest feedback from service users (questionnaires, calls), and random inspections of service providers as ways of measuring quality[126]

Other informal ways of monitoring quality have already been described in examples of best practice, e.g. the care plan, service user and staff surveys etc.

Mechanisms for raising concerns about quality:

- Service users are aware of a complaints procedure 'of sorts' but there is relatively low awareness of complaints channels. The few who *had* had cause to complain described it as a slow, negative and tedious experience – but with satisfactory resolution through negotiation[127]

- In a consultation among stakeholders,[128] the Department of Health had to confirm that there was indeed a standard mechanism for local authorities for people accessing care, with regard to enablement and appeals process

General points on mechanisms for raising concerns about quality:

- Providers stated that any mechanism for monitoring quality/raising concerns about quality needs to focus on *outcomes* rather than *regulation[129]*

- The general public feels that accountability is too often framed in a negative sense, i.e. what to do when things go wrong, rather than focusing more on outcomes[130]

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[122] Ref 1 (Stakeholders)
[123] Ref 30 (General public)
[124] Ref 1 (Stakeholders)
[125] Ref 4 (Social care staff)
[126] Ref 7 ('Unengaged' general public)
[127] Ref 17 (Older people, people with disabilities and people with learning difficulties)
[128] Ref 22 (Stakeholders)
[129] Ref 1 (Stakeholders)
[130] Ref 30 (General public)

7.0 Markets

Four question areas were explored:

- Definition of social care market

- Efficient working of the social care market

- Oversight of the social care market

- Impacts of reforms to the social care market

Overview

There are different perspectives on the definition and scope of the social care market within and across audiences, although no consensus emerges

Coverage of the efficient working of the market is fairly limited, although arguably, there is some overlap here with coverage on how to improve quality of social care (Quality and Supporting the Workforce)

Coverage of future impact of reforms is low, and limited to views from providers and stakeholders

Coverage of oversight of the social care market is low, with no over-arching themes emerging

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7.1 Definition of the social care market

General public's perspective

- Has limited understanding of the care and support sector[131] – 57% know not very much/nothing at all about the care system, and 50% are unaware that it is being reformed

- 'Social care' is not a widely recognised term and 20% are unable to describe what they understand by this term

- Most commonly, 'social care' thought to include home/day care for older people (45%) or for people with disabilities (26%) and residential/nursing care for older people (20%)[132]

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[131] Ref 27 (General public/stakeholders)
[132] Ref 5 (General public)

Stakeholders' and carers' perspective[133]

- Struggle to distinguish between care and health services, especially those services provided by NHS

- They have difficulty in reconciling social care with health care systems, with no way of distinguishing personal care from health care

- Long-term care is seen as partially falling within health care, while personal care falls within social care that helps people with everyday living

Staff and service users' perspective[134]

- Unclear about which services/professions belong under the social care umbrella

- 'Social care' is not a term used by service users, or recognised as a universal descriptor by managers and frontline staff

- Service users define social care in terms of its role as a service and financial support mechanism to those vulnerable or challenged (physically or mentally) in everyday life, people working within it, services provided, and service users it helps

- Service users feel there is a need to be clearer about what social care *is* (and what it is *for*)

- Most managers and frontline staff do not consider social care to be a unified industry, and care workers do not necessarily see themselves as part of the same sector

Different dimensions to be considered when defining the social care market:

Providers' perspective[135]

- Sectors/areas of expertise: older people, older people with dementia, mental health, learning disabilities, drugs or alcohol misuse

- Size of provider: small versus large number of residential care homes

- Type of provider: domiciliary care versus residential care

Service users' perspective[136]

- People who set up and organise care (paid, unpaid) versus people who provide care (paid, unpaid)

- Different types of service within social care: nursing, special facilities, anti-social behaviour

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[133] Ref 14 (Desk research, social care audiences)

[134] Ref 4 (Desk research, social care audiences), 65 (Social care users, general public)

[135] Ref 1 (Stakeholders)

[136] Refs 17 (Older people, people with disabilities, people with learning disabilities), 65 (Social care users), 77 (Social care users, employers of care and support staff)

- Help with everyday tasks versus provision of facilities that allow people to achieve things themselves versus machinery of mobility

- Activities conducted in and outside the home

Delivery of social care as perceived by service users, general public[137]

- Role of Government is primarily the funding and allocation of budgets

- Role of NHS is one of access points to services on the basis of health needs, through GPs or hospital doctors. It also has clinical role in supporting users to stay healthy and independent

- Role of Local Authorities is as employers of social workers and social care staff and practical providers of facilities

7.2 Efficient working of the social care market

- Many service users are unsure how to access social care services, even where they have indirect experience of social care - it is not planned, and there is a steep learning curve from ignorance to extreme need, the biggest hurdle being access to services and information[138]

- Other hurdles include bureaucracy, being passed between agencies, contradictory information about financial entitlement, lengthy timeframes[139]

- Navigating and accessing the system is especially difficult for older people with impairments[140]

- Stakeholders believe that many people are not getting the help they need because of funding and staff shortages, difficult navigation around the system and lack of joined-up working between providers; particular groups affected are those with low to moderate needs, older people who move between care statuses, and those with long-term degenerative conditions[141]

- Key recommendations for access to information, advice and advocacy *(IDeA, Transforming Adult Social Care: access to information, advice and advocacy, 2010):*[142]

    1. Transformation and personalisation dependent upon good information, advice, advocacy, support planning and brokerage
    2. Framed in the context of interpersonal support, underpinned by safeguarding
    3. Framed in three dimensions: managing information, awareness/knowledge, and delivery mechanisms

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[137] Ref 14 (Desk research, social care audiences), 17 (Older people, people with disabilities, people with learning disabilities)
[138] Ref 14 (Desk research, social care audiences)
[139] Ref 14 (Desk research, social care audiences), 28 (Seldom heard general public)
[140] Ref 28 (Seldom heard general public)
[141] Ref 27 (General public)
[142] Ref 52 (Stakeholders/general public)

4. Market the sources of information, advice and advocacy services available currently

5. Build statutory information base on the current DirectGov and local authority website core, and enhance access and links

6. Frame standards linked to efficiency: affordability, availability, quality, appropriateness, type

7. Map and model the ideal type based on national / local provision and delivery

Areas for driving greater efficiency

General public's perspective

• Members of the general public with experience of the social care system feel that a wider range of care needs should be better supported, beyond those narrowly defined as 'personal care', as arbitrary divisions can lead to neglect of other areas *e.g. help with domestic tasks*[143]

Stakeholders' perspective[144]

• The third sector provides valuable care and support in some settings, and this good practice should be identified and built upon

• Develop and strengthen the relationship between local authorities and the voluntary sector

• Address relationship weaknesses between NHS and social care, and adopt set of values for social care that is closer to that of NHS ('on the side of the user')

• People generally don't want to live in residential care homes, yet yearly half a million do. This is presented as the only option – present others

Staff's perspective[145]

• DH should consider developing a segmentation of needs among users/potential users, to include an evaluation of target audiences for social care and an examination of the events that trigger the need for social care services among each target

• There are also consumer typologies identified in relation to social care and needs (2007)[146] which, the author suggests, could be reviewed and refreshed

7.3   Oversight of the social care market

• Only some stakeholders and members of the general public think that the Government should have overall responsibility for the regulation of service[147]

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[143] Ref 34 (General public/stakeholders)
[144] Refs 23 (General public/stakeholders), 25 (Stakeholders)
[145] Ref 14 (Desk research, social care audiences)
[146] Ref 12 (General public)
[147] Ref 25 (Stakeholders)

Other approaches to oversight, including measures to address provider failure, have been referenced in the section on quality and supporting the workforce – for example, the SCIE Excellence Award and other quality assessment schemes

7.4   Impacts of the reforms to the social care market

The comments below generally pre-date 2011

- Stakeholders voice concerns that focus will change from outcomes back to tasks, contradicting current direction (2010)[148]

- The Joseph Rowntree Foundation (2010)[149] points to

    - strong fears among service users about a 'two tier system', as in US health care system, and associated concerns that people might be excluded from insurance by increasing use of genetic testing
    - importance of fairness, *for example, is there a desire to equalise care that people on lower incomes receive as opposed to that which people on high incomes might buy for themselves?*
    - need for Government to state its intentions both as purchaser and supplier to ensure understanding of what the state will and will not provide in the future
    - what are the unintended consequences of making an intervention in one part of the system, on other parts of that system?

- Leonard Cheshire Disability (2008) stated that the direction of travel for social care is not consistent with key government policy objectives of early intervention and a culture of independence and choice – in particular for disabled people; and that a strategy for tackling disability poverty should be implemented)[150]

- Some service providers raise concerns about the potential risks of the growth of the Personal Assistant market - cost-driven decision-making and deregulation (2011)[151]

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[148] Ref 22 (Stakeholders)
[149] Ref 65 (General public, social care users)
[150] Ref 67 (Disabled people)
[151] Ref 1 (Stakeholders)

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