

# **Caring For Our Future Engagement: Analysis of Responses**

Prepared for the Department of Health

February 2012

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# Executive Summary

# Executive Summary

## Background

The 'Caring for our future' engagement was a discussion with the care and support community, voluntary sector, service users and carers which gathered views on the immediate and longer-term priorities for reforming the care and support system.

The engagement focused on six priority areas identified as having the biggest potential to make improvements to the care and support system. Feedback was also sought on the Dilnot Commission's recommendations on the funding of social care:



The engagement took place between 15 September – 2 December 2011. A number of different mechanisms for people and organisations to comment on the seven priority areas were provided:

- A **feedback form** that could be downloaded from the 'Caring for our future' website
- A resource pack, supporting stakeholders to run their own discussions and events that covered the questions in relation to the seven priority areas outlined above. An **event feedback form** was also provided

- Commenting directly on the priorities section of the 'Caring for our future' **website**
- Participating in two **web chats** held on 18 October and 29 November
- Other **response formats** sent by organisations or individuals (not using the feedback form template)

Responses to the engagement will feed directly into a White Paper that will be published in Spring 2012, alongside a progress report on funding reform. The White Paper will set out the Government's approach to reform, to start the process of transforming England's care and support system.

There were **565 responses** to the engagement. The number of responses via each channel is shown below.

Channel	Number of responses
Web forms	280
Event feedback forms	92
Event reports/minutes	31
Web comments	88 respondents (170 comments)
Web chat comments	27 respondents (37 comments)
Letters	17
Reports	30
<b>Total</b>	<b>565</b>

Please note that the totals for web comments and web chat comments are based on the numbers of individuals/organisation contributing via each channel. The figures in brackets show the number of comments made. Some comments were also made in other sections of the 'Caring for our future' website (for instance on blogs/updates) but these have not been included in our analysis but have been noted by the Department of Health.

In addition, 22 responses were received by the Department of Health on its 'Oversight of the social care market' discussion paper. The Department has conducted its own analysis of these responses.

Responses were received from a wide range of organisations and individuals including people who use services and their carers, local authorities, voluntary and community organisations, user-led organisations, local involvement networks, NHS organisations, professional bodies, national representative organisations, charities, care providers and care practitioners. Many of the submissions comprised detailed, well-researched arguments.

A list of the organisations taking part and the events for which feedback forms were submitted can be found in the appendices.

Ipsos MORI has been commissioned to provide an independent analysis of the engagement responses. Responses were coded into a spreadsheet organised into seven priority areas, with data grouped by the issues asked about in the feedback forms. The analysis of these responses has been qualitative in nature, identifying the main themes raised by respondents.

This work is intended to inform and complement the separate analysis of responses which has been undertaken by the relevant policy teams in the Department of Health. Furthermore, through various forms of engagement with stakeholders and members of the public, the Department of Health has been able to hear first hand many different perspectives on care and support. There are a large number of specific, detailed points which the Department has noted and taken forward in developing the White Paper and progress report on funding, but which due to the nature of this document could not be included. This document is one of a number which will inform the Government's White Paper and progress report on funding.



## Overview

The key themes emerging from the engagement are consistent with what has been found in previous consultations, reviews and research.<sup>1</sup> In particular, the need for reform of social care funding, the importance of quality, the key role of information and advice for service users, the benefits of integration and prevention, enabling users and carers to shape services and the requirement to develop the social care workforce.

The following cross-cutting themes were identified across the seven priority areas:



Providing effective information and advice underpinned all the priority areas. Involving users was another recurring theme, with carers also mentioned by some. A range of different approaches was suggested, from eliciting user feedback through existing mechanisms to co-producing services with users.

Developing and training the social care workforce was cited as a priority for delivering improvements in quality, personalisation, integration and prevention. Innovation was another thread which ran across different areas because of the potential of new approaches (including new technologies) to improve the provision of social care.

Funding was another recurring theme across responses, both in terms of the investment required to achieve change and the increase in funding required to improve social care.

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<sup>1</sup> See for example 'Caring for our future': COI desk research to help inform the approach (October 2011)

It is also worth pointing out the extent to which the seven priority areas interlink. For example, a vibrant and diverse market and improved quality were both seen to have a key role in achieving better personalisation. There is also a strong interplay between integration and prevention, while the financial services market is seen to have a crucial part to play in underpinning reforms to the funding of the social care system by helping people to plan and prepare.

### **Quality and workforce**

- The importance of quality was explicitly or implicitly recognised by all respondents who commented on the issue. The balance of opinion was just in favour of a standard definition, although the need to acknowledge user perspectives and local variations within this were raised by a number of respondents. User-defined outcomes and local/service diversity were the most common reasons given for opposing a standard definition, and the difficulties in finding a common definition were also raised.
- A wide range of views was expressed on defining quality, from 'soft' outcomes such as dignity to hard metrics such as value for money. However, most of the definitions suggested were user-centred, highlighting that any definition of quality should include this perspective. The need for common guidance on standards was generally agreed.
- Developing a national set of standards was seen by some respondents to be an important element in making quality a guiding principle. Most respondents who expressed a view on the issue favoured a national framework with the scope for flexibility and interpretation at local level.
- Some respondents supported the use of outcomes frameworks. Regulation, staffing, commissioning, information provision and user feedback were also suggested. The TripAdvisor model was mentioned, although concerns were raised about this.
- There was widespread agreement among the respondents who commented on the issue that the social care workforce is undervalued and underpaid. There was strong support for improved training and development. This was seen as key to improving the image of social care employment. Increasing pay, providing clear career paths and valuing the workforce more were also viewed as important priorities for raising quality standards.

- Turning to the role of carers in improving quality, a number of respondents argued that they have a crucial role in the social care system. Equipping them with information, advice, training opportunities were all mentioned, as was involving carers in shaping local services.
- When discussing the impact of personalisation on the approach to quality, the importance of user involvement was stressed. This ranged from gathering user feedback through to user input into the design of services.
- The need to ensure effective mechanisms to raise concerns about the quality of care was widely accepted. While some felt that current structures are adequate, more argued that improvements are required so people are both aware of where they can complain and can be confident that their concerns will be acted upon.

### **Personalisation and choice**

- There was wide acceptance of the need for a culture change within the social care workforce to support personalisation. This included winning the hearts and minds of the workforce by communicating the benefits of personalisation, staff training (which some suggested should include user involvement), strong leadership at all levels and breaking down barriers such as lack of funding and concerns about risk.
- A number of groups of service users were identified as missing out from personalisation: the very old, people with mental health issues such as dementia, people with learning difficulties, people at the end of life, and people with sensory impairments.
- Appropriate information and support was perceived as critical to achieving personalisation. Several respondents highlighted specific areas where information is required such as guidance on personal budgets, comparing services and employment issues.
- A number of respondents argued that information should be provided in a range of formats to meet different needs. Terminology should be used consistently and information should be accessible. User organisations and voluntary groups could be involved in this. Advocacy was seen to have a key role to play, and some suggested the ability to pay for this from personal budgets. A number of

respondents argued advocacy services are best delivered by other service users.

- Applying the principle of personalisation to residential care was favoured by most respondents who commented on this issue. The general view was that the type of care provided should have little bearing on the principle of personalisation.
- There was much greater caution on the issue of extending direct payments to people living in residential accommodation. Respondents raised concerns around safeguarding and what individuals would be charged.
- A number of barriers to personalisation were identified – service user reluctance, staff attitudes, funding cuts and the lack of choice available. Information, advocacy, effective joined up working, service user involvement, framework arrangements to monitor progress and reviewing people's outcomes were all suggested as ways to tackle these barriers. Another key factor raised was stimulating the market to ensure a greater range of provision.

## **Integration**

- The need for better integration is taken as a given by almost all respondents. There was a wide range of views about what 'good integration' should look like, although being person-centred and involving good outcomes were common themes. A continuum of responses emerged, starting with a basic definition that the user is happy and ending with a total integration of organisations and budgets. Some rejected the idea of a common definition, while others queried whether full scale integration is appropriate.
- On the specific issue of which services should be better integrated, four key themes emerged – transition points such as the discharge from hospital, integration across all public services (with housing and employment being particularly mentioned), information and communications, and equality of opportunity for different groups.
- Better user outcomes were seen to be a key benefit of integration, with cost effectiveness seen as a less important concern. If people receive the right services in the right place at the right time, the view was that this should reduce bureaucracy, duplication and waste.

- The barriers to integration were seen to be structural, cultural and financial. Structural barriers included separate budgets and data systems, and lack of common standards. NHS reorganisation was also raised. Cultural barriers included different models of care ('social' vs 'medical'), distinct organisational cultures and a lack of willingness to work together. Resource constraints and the need to fund the cost of integration were seen to be significant financial barriers. Health care being free at the point of delivery while social care is means-tested was also mentioned.
- In the submissions addressing this priority area, there was clear enthusiasm to make integration work. Strategic direction from the national government and health and wellbeing boards at the local level were both seen to be key. Communications and information were also identified, in particular the alignment of data and information between different agencies. 'Smart' technology was seen to have a role in this respect. Finally, some respondents suggested pooling budgets to create more flexible funding streams.

### **Prevention and early intervention**

- There was a general consensus around the importance of prevention. Good outcomes are generally determined from the perspective of the user, with a wide range of suggestions made as to how to define these. Enabling people to live independent lives and quality of life were mentioned most often. Some respondents looked at this issue in terms of reducing levels of interaction with social care and health services.
- When considering how to work together to invest in prevention and promote wellbeing, respondents made a number of suggestions, with comments on funding preventative services and effective joint working receiving the most mentions. Sharing best practice and equipping users, carers and professionals with information on the preventative services available were also raised. The voluntary sector was seen as having an important role to play by some respondents, while others talked about the importance of housing in this context.
- Some felt incentivising good practice was vital to change cultures and behaviours around prevention. Sharing good practice, strong leadership and training were also suggested. Eligibility criteria were seen to work against the

preventative agenda as people with low or moderate care needs were excluded from services.

- There were few concrete suggestions around the mechanisms for payment by results. While some respondents supported this principle, others raised concerns about the difficulties in measuring results in complex preventative services.
- Turning to the issue of nurturing innovation, a number of ideas were mentioned, including promoting best practice, providing evidence for the value of prevention, building innovation into the commissioning process and funding pilots.
- Responses to the question of how to encourage individuals, families and communities to take responsibility for their health and wellbeing fell into five broad areas: provision of information about healthy living, promotion of healthy living, provision of appropriate facilities, empowering individuals to take more responsibility, and placing further restrictions on unhealthy choices such as smoking.

### **Shaping local care services**

- There was no clear consensus on how to define the social care market, with responses focusing on services required by individuals, types of care provided, types of providers and types of user groups. Several respondents argued for a broad definition of the market, while a handful queried the application of the concept of a market in the context of social care.
- A wide range of suggestions were made to increase the effectiveness of the social care market. Information provision was raised most often. Providing users and carers with information on available services was one element of this, while equipping providers and potential providers with market data was another. The need to stimulate the market by encouraging small and/or new providers was discussed by a number of respondents. More effective commissioning was also seen as having a key role to play. Working in partnership with the third sector and providers was another suggestion.
- Turning to the issue of further oversight of the care market, some respondents felt that greater market regulation of large providers is required to ensure they remain financial viable, although some concerns were raised about this. Other

respondents suggested strengthening the role of the Care Quality Commission through greater enforcement powers and more resources. However the work of the Care Quality Commission was criticised by some respondents.

- There were relatively few responses to the question of whether further measures to address provider failure were required. Most suggestions were on the theme of contingency planning, with the overall aim of ensuring service continuity.
- When discussing the impact of the wider reforms to the social care system on the market, there were both positive and negative responses, with the balance in favour of positive comments. Wider reform of the care and support system was seen to have the potential to increase choice and control, create more flexible and responsive services and increase diversity of provision. Among the concerns raised were the danger of services become more costly, the risk of market fragmentation and smaller providers finding it more difficult to compete.

### **The role of financial services**

- In discussing the barriers to the development of financial products that help people to plan for and meet the costs of care, respondents raised the public's perceived unwillingness to plan for the future, a lack of understanding of their potential care needs, the perception that care is the responsibility of the state, a lack of funds and the complexity of products. Mistrust of the financial services sector was the most common barrier, and this thread ran throughout responses to this priority area.
- Fewer comments were made from the supply-side perspective, but concerns were raised about profitability, poor take-up, and the unpredictability of the risk.
- Most respondents who addressed this issue felt that the Dilnot Commission's recommendations would, at least in part, overcome these barriers. The clarity provided by the reforms to both individuals and financial services providers was mentioned most often.
- On the issue of the role of the government in making it easier for individuals to plan for the future, three broad themes were raised: raising awareness of the need to do so, providing information and offering financial incentives.

- Turning to the issue of the wider involvement of the financial services industry, raising awareness of the need to plan, help with financial planning and providing information were raised most often.
- A handful of respondents rejected outright the financial services sector having any role in the funding of social care. More commonly though, respondents raised concerns about the poor image of the financial services industry, pointing out that it is important that individuals are protected from being exploited through safeguards and regulation.

### **The Dilnot Commission's proposals**

- The broad thrust of the Dilnot Commission's proposals were supported by almost all respondents. While concerns were raised about certain elements of the proposals, the general sense was that they are the best solution on the table. The few respondents who opposed the recommendations generally did so on the basis that social care should be free at the point of delivery and funded through general taxation.
- The key strengths of the Dilnot Commission's recommendations were seen to be their fairness, clarity, sustainability and consistency. The engagement also asked about the weaknesses of the proposals, and responses on this issue generally focused on the detail such as the complexity and bureaucracy involved in monitoring costs and the recommendation to set eligibility criteria at 'substantial', which works against the preventative agenda. More fundamental concerns centred on the argument that the proposals do not resolve the current underfunding of social care. The comments on weaknesses were generally offered in the spirit of general support for the Dilnot Commission's proposals.
- When discussing the implications of the proposals, responses generally focused on the cost of funding and resourcing the reforms. The impact of standardising eligibility criteria across different local authorities was also raised, as was the impact on benefits.
- Turning to the specific detail of the proposals, several respondents supported the level of the lifetime cap on social care costs being set at £35,000. Some felt it should be higher while others argued it should be lower. A number of respondents simply stated their support for the principle of a lifetime cap without discussing what level it should be set at. There was little specific comment on



the level of contribution to accommodation costs in residential care, but some respondents felt it could cause confusion and difficulties if individuals remain responsible for these costs, while others queried how the costs would be calculated.

- In considering the priorities arising from the Dilnot Commission's report, many respondents made the general argument that the proposals should be implemented, as the opportunity to reform the funding of social care must be seized. In addition, implementing the Law Commission's proposals to reform social care law was supported by all those who mentioned this.
- In terms of more specific priorities, all of the key recommendations of the Dilnot Commission received support, with the cap on lifetime contribution to care costs, increasing state funding for social care, a national system of eligibility and assessments and a national information and advice system receiving the most mentions.

# **Background to the engagement and the analysis**

# Overview of the engagement process

## Background

The 'Caring for our future' engagement seeks to understand the immediate and longer-term priorities for social care reform among people who use care and support services, carers, local councils, care providers, the voluntary sector and other interested parties.

The engagement builds on a body of work already conducted in this area. In November 2010, the Government published '*A vision for adult social care: Capable communities and active citizens*' which set out the principles for a modern system of care and support. In '*Recognised, valued and supported: next steps for the Carers Strategy*', also published in November 2010, the Government set out its priorities for helping carers.

**Three other major reports** have shaped the debate on the future of social care:

- The Law Commission's report '*Adult Social Care*', which set out recommendations for the simplification of social care law (May 2011)
- The Commission on Funding of Care and Support's report '*Fairer Care Funding*' (July 2011) published recommendations for reforming the way that people pay for care and support
- The Palliative Care Funding Review (July 2011) sets out proposals to ensure integrated, responsive, high quality health and care services for those at the end of life

The engagement is based around **six priority areas** identified as having the biggest potential to make improvements to the care and support system.

- **Quality and workforce:** what are the priorities for improving quality and developing the future workforce?
- **Personalisation and choice:** what are the priorities for promoting increased personalisation and choice?
- **Integration:** how can we take advantage of the Health & Social Care modernisation programme to ensure services are better integrated around people's needs?
- **Prevention and early intervention:** what are the priorities for supporting greater prevention and early intervention?

- **Shaping local care services:** what are the priorities for creating a more diverse and responsive care market?
- **The role of financial services:** what role could the financial services sector play in supporting care users, carers and their families?

As a **seventh priority area** for discussion, the engagement also sought views on the recommendations made by the Commission on Funding of Care and Support on the **priorities for funding reform**. Please note that the Commission on Funding of Care and Support is referred to as the 'Dilnot Commission' throughout this report.

The engagement took place between 15 September and 2 December 2011. A number of different mechanisms for people and organisations to comment on the seven priority areas were provided:

- A **feedback form** that could be downloaded from the 'Caring for our future' website
- A resource pack, supporting stakeholders to run their own discussions and events that covered the questions in relation to the seven priority areas on the next steps in social care reform. An **event feedback form** was also provided
- Commenting directly on the priorities section of the 'Caring for our future' **website**
- Participating in two **web chats** held on 18 October and 29 November
- Other **response formats** sent by organisations or individuals (not using the feedback form template)

Responses to the engagement will feed directly into a White Paper that will be published in Spring 2012, alongside a progress report on funding reform. The White Paper will set out the Government's approach to reform to start the process of transforming England's care and support system.

As part of the engagement process, six reference groups were set up for the quality and workforce, personalisation and choice, integration, prevention and early intervention, shaping local care services, and the role of financial services workstreams. A key member of the care and support community led each reference group. Each discussion lead ran a range of meetings with interested parties. In addition, four stakeholder events were held in November and December, led by the six discussion leads and involving members of their reference groups and policy

colleagues at the Department of Health. For full details of the membership of each reference group, please see the appendices.

Please note that the work of the reference groups and the outputs of the stakeholder workshops have not been analysed for the purposes of this report. This analysis has been undertaken by the social care policy team at the Department of Health. Details of the workshops can be found at <http://caringforourfuture.dh.gov.uk/>.

## Responses

There were **565 responses** to the engagement. The number of responses via each channel is shown below.

Channel	Number of responses
Web forms	280
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In addition, 22 responses were received by the Department of Health on its 'Oversight of the social care market' discussion paper. The Department has conducted its own analysis of these responses.

Responses were received from a wide range of organisations and individuals including people who use services and their carers, local authorities, voluntary and community organisations, user-led organisations, local involvement networks, NHS organisations, professional bodies, national representative organisations, charities, care providers and care practitioners. Many of the submissions comprised detailed, well-researched arguments.

A handful of respondents submitted the same response through more than one channel. Where this happened, only one response has been considered for the purposes of analysis. In a few instances, organisations submitted more than one response. If the content and/or author was substantially different, these were analysed separately. If there was significant overlap and/or the author was the same, they were analysed as one response.

A list of the organisations taking part and the events for which feedback forms were submitted can be found in the appendices.

## **Analysing and interpreting the data**

The responses received were coded into a spreadsheet organised into the seven priority areas, with data grouped by the issues asked about in the feedback forms, and space for additional comments.

Our analysis of this data has been qualitative in nature. Qualitative methods are much-used and well-respected in research. Despite the fact that findings emerge as a number of 'themes' and 'ideas' rather than leading to statistical analysis, this can be just as, if not more, useful in analysing results. A number of verbatim comments are included to illustrate and highlight key issues raised.

It is not possible to encapsulate all the important and detailed issues from responses and do justice to the amount of work that has been put into many of the responses in this summary document. Throughout this report, we have sought to include recurring themes emerging from responses, rather than detailing specific, individual issues or outlining every point of view. Our focus has been on understanding responses to the questions posed in each of the priority areas, although many responses ranged much wider than this.

At the request of the Department of Health, we have highlighted examples of best practice given by respondents, as well as practical suggestions as to how to achieve

some of the priorities discussed. The Department of Health also asked us to analyse three specific topics – carers, equalities issues and end of life care – and we have produced a section on each in the chapter on cross-cutting themes.

We have been asked to undertake the analysis of the engagement responses as an independent research organisation. We have not applied any weighting to the views of different respondents taking part in the engagement as it would not be appropriate to ascribe different degrees of importance to participating organisations and individuals.

This work is intended to inform and complement the separate analysis of responses which has been undertaken by the relevant policy teams in the Department of Health. Furthermore, through various forms of engagement with stakeholders and members of the public, the Department of Health has been able to hear first hand many different perspectives on care and support. There are a large number of specific, detailed points which the Department has noted and taken forward in developing the White Paper, but which due to the nature of this document could not be included. This document is one of a number which will inform the Government's White Paper.

## **Partners**

The Department of Health appointed the Central Office of Information (COI) to work with the Department during the analysis of the engagement.

Ipsos MORI were appointed from COI's External Engagement Framework, following a competitive tender, to analyse the results of the engagement and report back to the Department of Health as an independent body.

# **Analysis of the engagement responses**



# **Quality and workforce**

# Quality and workforce

## Engagement questions

### 1. What are the priorities for promoting improved quality and developing the future workforce?

- a. Should there be a standard definition of quality in adult social care as quality can often be interpreted differently? What do we mean by it and how should it be defined? How could we use this definition to drive improvements in quality?
- b. How could the approach to quality need to change as individuals increasingly fund or take responsibility for commissioning their own care? How could users themselves play a stronger role in determining the outcomes that they experience and designing quality services that are integrated around their personal preferences?
- c. How could we make quality the guiding principle for adult social care? Who is responsible and accountable for driving continuous quality improvement within a more integrated health and care system?
- d. What is the right balance between a national and local approach to improving quality and developing the workforce? Which areas are best delivered at a national level?
- e. How could we equip the workforce, volunteers and carers to respond to the challenges of improving quality and responding to growth in demand? How could we develop social care leadership capable of steering and delivering this?
- f. How could we improve the mechanisms for users, carers and staff to raise concerns about the quality of care? How could we ensure that these concerns are addressed appropriately?

## Defining quality

### A standard definition?

Respondents' views on whether or not there should be a standard definition of quality in adult social care are difficult to unravel, partly because of semantics and partly because of the way respondents reacted to other elements of the engagement.

There was no overwhelming view that a standard definition of quality is either desirable or possible. Although the balance of respondents said they favoured a national definition, some of them actually proposed *common standards* rather than a *national definition*.

Those who favoured a national definition did so on the basis that it 'would be a good starting point' for understanding what good social care should look like, in a way which would be generally understood. Without such an understanding, they felt that the system just would not be fair across the country.

It was argued that quality of care should not differ according to variables such as price, source of funding, or type of care. This, it was argued, would result in a two-tier workforce and drive poor practice underground. Many respondents commented that there is already a 'postcode lottery' in the availability and quality of care, arising from differing local authority practices and policies, and their implementation of the Fair Access to Care Services (FACS) criteria.

Further, without a national understanding of care quality, some argued that minority community service users may be at risk because numbers of service users could be insufficient to make the development of specialist services economically viable at a local level.

These respondents therefore argued for standardisation through a commonly agreed user-focused definition which could engage, and generally raise awareness among, service users, carers, commissioners, regulators and the public about the standard of care they should expect. A standard definition of quality could drive improvements by making it integral to a set of national workforce standards for staff, potentially linked to pay and conditions and a clear career path.

A number of suggestions were made for using existing definitions, such as the (SCIE) for Excellence's definition of excellence by service providers and staff, Dignity in Care principles, Care Quality Commission's Essential Standards, the 360 standard

framework, or the old Care Quality Commission star ratings, although not everyone agreed that they would be appropriate.

*A standard definition should be simple and use accessible language, promoted through staff communication and support/training arrangements and actively used to engage with service users, their organisations and representatives. A standard definition should be used in service commissioning specs and via educational commissioning.*

NHS Midlands and East

*There is a risk that, without a clear definition of what good quality is, assured through a robust regulator and inspection regime, that individuals could receive care at a sub-standard level.*

Turning Point

Some respondents considered that, although standard definitions would be helpful, the detail has to come from the commissioner-provider-user relationships through feedback and discussion.

And this is perhaps the key issue, because the arguments against a standard definition by local authorities and other statutory organisations, partly focused precisely on this point. It was that very need to reflect local activities and relationships that made a national definition difficult to agree. Tyneside Council said it was difficult enough to get agreement within a region about quality, let alone nationally, given the diversity between local authorities arising from local financial circumstances and locally-determined policies.

Some users and carer groups agreed with statutory organisations on this point. They felt that individual agreements between user and provider, together with safeguarding arrangements to be triggered when there were problems, were more important than national definitions, which may in any case lead to unnecessary red tape.

*Excellent social care will be different for different individuals and it would be incredibly difficult to apply a single, practical definition that would be understood by everyone using services and not disadvantage some providers.*

United Kingdom Home Care Association

*Quality is a subjective and personal judgement. Delivery of personalisation and self-directed support should be a better driver of enhanced quality than standardised definitions and frameworks for care.*

Suffolk County Council

There is a way through this apparent difference of view, however. Most respondents, either implicitly (from other comments made) or explicitly, agreed that there should be some minimum standards, a 'bottom line' which should be adhered to in all circumstances, and progressively built upon over time.

*It is not possible to imagine a single definition of quality – we would prefer clear and measurable standards for each service area.*

St. Helens Council

Thus it may be possible to construct a very general *subjective* definition of quality which would be acceptable to most – for example:

*Promotion of social inclusion, treated with dignity and respect, promoting choice and opportunity.*

Halton Borough Council

*Quality is met when the outcomes of care ensure that a person feels respected, their health and social needs are met, and they are happy with those outcomes.*

Aylsham Manor care home

*Everything flows from treating people with dignity and respect.*

Middlesbrough Council

It would not be critical if these definitions were understood in different ways, as long as they are underpinned by *objective* minimum standards.

A set of nationally accredited quality standards for social care, underpinned by values such as dignity and respect could then be flexed locally to reflect local circumstances, and local/personal perspectives and priorities. These should be defined by professionals jointly with service users and their carers/families. There remain risks even with this approach, however. Some respondents, particularly carers or their

representatives, feared that 'minimum standards' could become 'acceptable standards' and actually act as a barrier to continuous improvement.

*Arriving at standard definitions of quality across a plurality of providers is complex but it is important that there is an agreed consensus of what constitutes good quality of care based primarily on measurable outcomes for service users.*

Involve, Yorkshire and Humber

*There should be a minimum standard definition of care to ensure consistency and fairness across the system, but it must be flexible enough to ensure that councils are free to make local decisions around attaining value for money, and to target resources on need, for the benefit of their local communities.*

Society of Local Authority Chief Executives

### **How quality should be defined and used to drive up standards**

If there was little agreement about whether there should be a national definition of quality in social care, there was less about what it might comprise. Service users and their representative groups tended to emphasise the importance of users' involvement with identifying and monitoring any definitions locally, together with the importance of good regulation. Statutory organisations, while often endorsing this, tended also to identify measurable outcomes. Many different aspects of care were identified as candidates for a definition of quality:

- **'Soft issues'**: care and compassion, meeting the needs of the individual, helping a person feel valued and respected.
- **'Practical issues'**: safety, cost-effectiveness, meeting outcomes, timeliness and accessibility.
- **'Staffing issues'**: the way a provider treats/manages staff – cared-for staff are in a better position to care for their customers; assessments of quality need to include measures of employee experience as well as customer experience.
- **'Outcomes framework'** between health, social care and public health, focusing on the needs of individuals and not the system or staff groups.

- **'Accountability issues'**, for example democratic accountability, delivered by providers who agree to work together.
- **'Clinical issues'**: care which is 'clinically effective, personal and safe', doing the right thing to the right person at the right time and doing things right first time. Together with, for example: timeliness and access to care; avoiding unnecessary procedures or those that are of minimal value; equitable; patient centred; and appropriate and acceptable.
- **Safeguarding issues**: robust accreditation system, strong regulation, learning from complaints.
- **'Efficiency and value for money.'**
- **'Communications'** between providers and, especially, with service users.
- **'Informal context'**: taking into account the good quality informal support that is provided by family and neighbours:

*There should be a combination of clear standards, easily measurable, which ensure that organisations are accountable for compliance, and that ensure improvement is acted upon, which promote consistency, are simple enough to be easily understood by the public and users of the services, and are influenced by service user feedback.*

Durham County Council

### **Standards of quality**

Although there was no consensus on whether there should be a national definition of care, or what it should comprise, respondents generally argued for clear national guidance on standards of quality that are measurable and have a service user perspective. The importance of clarity and avoiding bureaucracy, where possible, was also emphasised:

*A lot of resources have gone into the process of collecting data (often the wrong data) and manipulating the ill-fitting data to fit the systems of data collection. Where there has been an attempt to look at outcome data, the focus is mainly on one bit*

*of the patient / service user experience, not of the wider patient  
/ service user and carer experience of a pathway.*  
British Association of Social Workers

Practical suggestions for how to use quality definitions to drive up standards included:

- A 'getting the basics right' campaign, ensuring a core standard and creating a service user charter of expectations which is not simply based on a misleading measure of cost per hour to judge the value of one provider versus another. *'If purchasers are simply looking at cost per hour, it is difficult to see how good decisions will be made around any quality/price trade off'*. (Mears Group PLC)
- Investing in the inspection system. *'We have found that some of the companies we have worked with have not had an inspection since 2009 and this is clearly unacceptable and so is the excuse that there is a lack of 'man-power' within CQC. Other service industries are regulated much more closely.'* (Sheffield LINK, Local Involvement Network)
- Using incentives. These *'should be aligned at all levels in the health and care system. This would then drive the right behaviours, ensuring that a person centred approach is enshrined in the specification drawn up in contracts for commissioning of services'*. (Wiltshire and Swindon Users' Network)



## The interplay between quality and personalisation

Several respondents commented that councils need to ensure they have customer engagement mechanisms in place so the user voice is heard e.g. a standard tool kit to explain what quality is and how they should assess if they are getting it. It was pointed out that users are not always in a position to speak up to get the best care they should be entitled to. There were seen to be other key support roles for local authorities:

*The local authority's role will be to ensure people have the mental capacity to manage their money, that they have the necessary signposting and assistance to employ someone with an appropriate contract, and have a safeguarding response in place should they have an issue with the care they arrange.*

Hampshire County Council

A range of further additional suggestions for how users could play a stronger role in determining the outcomes that they experience, were as follows. (They were made, but not exclusively so, by those identified in brackets below):

- Development of a customer information portal to drive up quality through consumer feedback (Social Care Institute for Excellence (SCIE)).
- Not over-regulating services so that service users can, for example, employ friends, family or neighbours to provide care as their personal assistants, without too much emphasis on process and recording at the expense of dialogue with service users and carers about achieving real outcomes. (Hampshire County Council and Derby City Council).
- Monitoring should include a much larger proportion of service user views than at present (North Tyneside LINK, Local Involvement Network).
- Service users and carers should be actively involved in delivering training to social care staff (Plymouth LINK, Local Involvement Network).
- Information, advice and support should be made available to people who fund and/or commission their own care and their family/carers so that they know how they can make their personal preferences known to the care provider (Nottinghamshire County Council).

- User and carer involvement in engagement and monitoring quality is essential. Local ways of achieving this should be developed (British Association of Social Workers).
- There needs to be a stronger emphasis on user involvement in all phases of commissioning and care provision both at an individual and collective level. This requires more navigation and facilitation at complex interpersonal levels, and roles assuring the quality of provision and monitoring (NHS Midlands and East).
- The role of advocates and brokers will become more important. This will enable service-users to exercise choice, thereby feeding into the design of services. It is essential that there is sufficient capacity in brokerage and that those organisations offering brokerage have a full understanding of service-users' needs and that their services are fully accessible to service-users (Action on Hearing Loss).
- User experience of quality can be captured through technology, questionnaires, groups, use of reviews, user forums etc, together with the Local Involvement Networks/Local HealthWatch. There needs to be an easy and transparent method of feedback that also allows for a speedy response. By utilising technology, systems could be built which allow people to offer their opinions on a service prior to it becoming a full complaint (Halton Borough Council).

For these ideas to be taken forward, it was argued that there would need to be a number of things in place. A cultural change is required to encourage people to make plans and to talk to their families and relevant professionals about their preferences. This is difficult to achieve when people are not in need of any support, but needs to be encouraged as early as possible.

Another key theme raised was that care providers need to change their attitudes, listen to people more, be trained by users, and treat clients with respect - 'as adults'. This was identified frequently by service users' representatives, but was also reinforced by many others, including statutory agencies.

Some respondents pointed out that service users who employ their own staff are likely to have different needs arising from their new direct line of accountability. It was acknowledged, however, that this will need support in many cases, including information, often with effective brokerage. Local authorities expected to retain a key

role in formal support such as on legal aspects of employment and good practice as well as on service-related activities, and developing market information.

Pooling budgets could be an option for some commissioners. Sharing information was identified by many respondents as increasingly important for signposting users and supporting contract monitoring to drive improvements, either through existing forums and/or through HealthWatch. However, respondents pointed out that all this will not necessarily happen as a matter of course: resources and appropriately trained staff would be necessary for specialist support as well generic training aimed for personal assistants (PAs).

*The Council concurs with ADASS [Association of Directors of Adult Social Services] that reporting of accessible, user-friendly, up-to-date information on provider quality is particularly important to inform purchasing decisions, especially for service users with personal budgets making decisions about what to purchase for themselves.*

Durham County Council

Finally, several respondents pointed out the difficulties involved in regulating a personalised market:

*Regulating a personalised market will pose many challenges, particularly in ensuring that the process does not stifle choice, control and flexibility but it is essential in order to ensure that it is both safe and appropriate. This is an area that should be tackled early in the development process rather than putting it in the 'too difficult' box*

St Helens Council

## Driving quality forward

### Making quality the guiding principle

Several respondents articulated the view that everybody concerned has a role in making quality the guiding principle within a more integrated health and care system:

*Everyone should understand [guiding principles] - user, carer, staff, manager, inspector and commissioner.*

North Yorkshire County Council, quoting SPRUU

The most urgent need for respondents was the development of a set of national integrated standards which would be officially recognised and widely publicised. Within that context, respondents identified a range of approaches for making quality the guiding principle centred on performance management and staff quality:

#### *Staffing*

- Introduce baseline qualifications for staff, with an accreditation system to reach a standard required for all care staff.
- Develop a well-trained and well-supported workforce, valued as a caring profession, with appropriate pay and conditions, and a working environment not dominated by crisis work and overload.
- Promote a social care career pathway through care ambassadors linked to schools, further and higher education institutions.

#### *Regulation and performance review*

- Ensure regular performance review and continual staff/carer/user involvement.
- Make the Care Quality Commission (CQC) responsible for inspecting and improving standards, with the primary objective of providing advice and guidance to help providers to achieve higher standards.
- Introduce a challenging regulatory function which adopts a zero tolerance to safeguarding concerns, poor performance and a lack of dignity and respect, with appropriate enforcement action for services that are failing.

#### *Outcomes framework*

- Use outcomes frameworks for social care, public health and the NHS which are set nationally (locally the responsibility of health and wellbeing boards).

#### *Commissioning*

- Commission on quality as well as price.
- Encourage local commissioners only to contract with care homes where the registered manager is a member of the professional body, creating a lever for ensuring that managers are receiving professional supervision to deliver quality.

#### *Information, involvement and user monitoring*

- Ensure information is available for public and private service users to make decisions on services.
- Establish a forum to provide systematic feedback from providers, commissioners and service users, akin to TripAdvisor (see below).
- Improve communication between professionals, support workers, carers and service users. Some submissions made a very powerful case for the need for communications with service users to reflect users' particular, sometimes profound needs.
- Involve and listen to service users.

#### **The TripAdvisor model**

A number of respondents reflected upon using the model of TripAdvisor to rate adult care services. Some local authorities doubted the wisdom of this model, for example because of possible liability on the council, while some providers were concerned about vindictive comments:

*Just about every care home in the country receives at least one vexatious complaint from the public (usually relatives and friends of a resident and sometimes disaffected staff) every year. These would undoubtedly increase if a TripAdvisor website is invented.*

The Registered Care Providers Association (RCPA)

However, overall, respondents clearly welcomed this approach as a quick and effective means of communication of quality from the users' perspective.

*From a provider perspective, there is a clear case for empowering service users to make their own comments and ratings for services, as people do for hotels on the TripAdvisor website, for example. Worries about potential malicious reviews or legal action should not be allowed to override the need for clear information about services.*

Barchester Healthcare

### **Good practice case studies**

A number of case studies were provided by respondents to illustrate how they were already seeking to make quality the guiding principle:

- In the East Riding of Yorkshire, the Council's Quality Development Scheme (QDS) has been a positive influence on quality and standards of care, whereby providers who achieved the QDS award were acknowledged and financially rewarded. In the London Borough of Haringey, commissioners have developed their own local accreditation framework on which to base commissioning decisions; information on accredited services will be provided to service users who wish to commission their own care support.
- The Norfolk Coalition of Disabled People are developing a Care Services Users' Charter. All state-run providers would undergo training in responsiveness and how to contact additional professional providers who could be needed to assist the service user.
- The Hertfordshire Care Providers' Association supports local social care leaders and the development of leadership within the sector. They are funded by the sector and supported by the local authority. The PCT is also working with and through the organisation encouraging links with the other NHS organisations.
- In Newcastle, services receive a kite mark that demonstrates they have reached a quality standard; a directory of adult social care services is being developed which will include kite mark information; online information will allow service users and carers to comment directly on services that they have received.

### **Responsibility and accountability for driving continuous quality improvement**

No clear view emerged as to who is responsible or accountable for driving quality improvement. In fact just about every combination of interest group was mentioned by at least one respondent. As Bradford Metropolitan Borough Council suggested, this might point to the need for greater clarity about respective roles:

*Responsibility for setting and monitoring the standard of care and support is shared by the local authority and the NHS through commissioning practices; the CQC in its regulatory role; and service providers. There needs to be greater clarity about our respective roles and responsibilities.*

Bradford Metropolitan Borough Council

Some said everyone concerned with social care shared responsibility and accountability.

*Continuous quality improvement should be the responsibility of all parts of the care system, including service users not simply for consultation and feedback on pre-ordained plans, but as an integral part of design and planning as well as procurement, overall monitoring and quality assurance.*

NHS Midlands and East

Others focused on different aspects of the system.

- Commissioners and providers:

*It is the responsibility of the local authority and health commissioners, with providers, to drive quality improvements. Where there is a contract with a care provider, that contract should identify explicitly what role the local authority and/or health commissioners will play in driving quality improvements and what is expected and required of providers.*

Nottinghamshire County Council

- Providers:

*Quality is primarily the responsibility of the provider organisation delivering the care. However, it is also enhanced by effective regulation and inspection, effective commissioning, patient/client feedback, learning from complaints, system levers/incentives promoting quality or disincentives with the*

*opposite effect, quality of the workforce, and transparency and accessibility of information.*

NHS Confederation

- Regulators:

*Responsibility should lie with CQC as the regulators, and with health and wellbeing boards as the local experts working across health and social care and representing stakeholders within the community.*

Cambridgeshire County Council

- The Government:

*The overarching responsibility must rest with Government but the goal of achieving quality must be owned by everyone - service delivery systems, workforce, service users.*

National End of Life Programme

- Commissioners, inspection regimes and with providers:

*Accountability for quality within a more integrated system rests with commissioners, inspection regimes and with providers themselves. As providers, we must build partnerships with the individuals we look after, their relatives, our commissioners and all other stakeholders that reinforce our drive to improve services.*

Barchester Healthcare

- Local authorities:

*Local authorities should be at the centre of driving quality and continuous improvement for all users of adult social care, involving service users and the market to ensure that supply reflects genuine individual choice. Responsibility and accountability for driving quality is shared across commissioners, providers, service users and carers, professional bodies and CQC.*

London Borough of Barnet



- All public bodies:

*It is the joint responsibility of all public authorities not just Health and Social Care but also e.g. Police Service, Fire Service etc, Service Users themselves and the Voluntary Sector.*

Gateshead Access Panel

- Staff:

*Quality is clearly the responsibility of staff of all levels not just frontline staff but also management, national commissioners, families, carers and individuals. To ensure this responsibility is taken seriously it must be clearly defined from the outset, measured, reported on and validated.*

Turning Point

## **Improving quality and developing the workforce: national and local dimensions**

Respondents who expressed a view were for the most part very clear on this issue: a *national* framework should be set as a context for *local* delivery decisions.

*We believe that best practice standards need to be established at a national level; there can be no reduction in the quality or expectation of the quality of social care that is delivered just because we live in a different area. However, standards should allow room to reflect the local culture, and the wishes of individuals and local communities.*

Jewish Care

## **Improving quality: national and local perspectives**

Respondents generally favoured clear national regulation and guidance, which is then independently monitored to ensure that the standard of care delivered is appropriate, with scope for flexibility and interpretation at local level, allowing innovation. Service users and their families require an independent assessment of the quality of a service provider, especially those new to the care market. There were mixed feelings about the Care Quality Commission (CQC), discussed further below, but many felt that its star ratings should be restored for all care providers. They provided an easy way for individuals to distinguish between providers.

*CQC has the ability like no other organisation to judge the long-term quality delivery of a provider, for example by judging whether a provider has really delivered against a long term reablement based approach. We understand CQC's reluctance to do this, but if not CQC then who? The ratings should be easily accessible on a national website and have a local interface where individuals are able to rate their experiences of the service.*

Mears Group PLC

Local delivery, which some suggested could be in the form of a local charter, operating within a nationally-set framework, would enable the particular needs of the local community to be understood. This would ideally be paired with a single point of reference for information, including monitoring data from providers, which would be critical for service users' commissioning decisions. However there are currently many differences in the approach of local authorities, the frequently-mentioned 'postcode lottery', which would make it difficult to achieving a consistent quality and workforce strategy.

More formal, local initiatives were therefore suggested to share monitoring practices and data, which would facilitate like-for-like comparisons and increase service user knowledge. National, reciprocal agreements between local authorities to share monitored outcomes would also provide incentives to standardise national quality indicators.

However, there were a small number of cautioning voices about different, localised approaches potentially giving rise to duplication and confusion. Some national guidance was advised:

*The failures of national inspection regimes is evidence of [an over-reliance on national systems for improving quality]. The role of national organisations should be to act as advisors to local inspection units, including advising on the importance of including in inspection the impact of funding levels on providers.*

British Association of Social Workers

### **Case study**

Hampshire County Council set out its own model which could be used as a model in other areas:

*In Hampshire we have a local approach to improving quality through a robust Quality Outcomes and Contract Monitoring process, regular reviewing, and collaborative working with CQC. The local authority has a responsibility to ensure that minimum standards are met and to work with individual providers, CQC and Health to ensure issues of poor quality care are identified early and addressed to prevent safeguarding issues arising. Individuals exercising choice through commissioning their own care can play a part in improving quality but it is important to note that some service users have no capacity to exercise this choice.*

Hampshire County Council

### **The workforce: national and local perspectives**

*Nationally*, a number of aspects of workforce development were suggested:

- Registration, professional standards, and the setting of expectations regarding performance levels at individual and organisational level, as taken on in the work of Social Work Reform Board.
- Generic learning and educational commissioning, for example through the Skills for Care Workforce Strategy and the InLAWS (Integrated Local Area Workforce Strategy) framework.
- Development of robust data and intelligence systems to support workforce assurance.
- Development of national occupational competences and a pathway of learning, from management of services to competence of working with service users:

*The current balance between local and national is actually quite good. Skills for Care provide a lot of national guidance and support and are good at representing employer issues. The challenge is in making the aspirational vision a reality - there is already a wealth of good practice guidance but the reality is that providers still choose to ignore it, or see it as too costly or time consuming - e.g. training and development, good recruitment practices.*

Kirklees Council

Locally, it was suggested that local authorities would be best placed to identify training and development needs in the workforce which respond to commissioning priorities and plans, working with providers and non-statutory organisations. Local planning for workforce development could be carried out by joint local workforce boards as part of the new system of Local Education and Training Boards.

*The local agenda should be driven by local workforce planning (population-centric type approach) - putting the service user at the centre of what we do and the skill mix then driving this; training needs analyses, identifying skills gaps.*

Leeds City Council and Leeds CH Trust

## Equipping the workforce, volunteers and carers

### The workforce

There was little disagreement between respondents on what needed to be put in place to equip the workforce to respond to the challenges of improving quality and growth in demand. Two main sets of issues were raised – the practical one of training and accreditation, and the more radical one of changing the way in which care staff are generally perceived, by themselves as well as by the public. Workload was also mentioned.

The context was also generally agreed – that the social care workforce is undervalued and underpaid and that action is needed to create a workforce which is confident, appropriately trained, qualified and empowered.

*I am not aware of any current programmes to address the problems of the current social care workforce - hard work, long hours, low pay, little job security, etc. It is clear that the area requires proper professionalisation to prevent it being the preserve of the migrant worker, the school-leaver and the short term job hunter.*

Carers' Union

*It is a miracle that the current system works at all... The quality issues are all with the workforce - inappropriate hiring by providers, poor management and supervision, lack of training, poor pay, unpaid travelling time, call cramming, call times*

*insufficient for task to be performed.*

Individual

### **(i) Training and development**

The general view was that the social care workforce, particularly in its lower tiers, is less well trained than the NHS workforce and has fewer opportunities for professional development.

It was argued that workforce strategy at local, regional and national levels could underpin and interlink with adult social care strategic objectives, covering workforce data, workforce re-design, an autonomous workforce, providing learning, qualifications and standards, recruitment and retention policy, and having strong leadership and management. The new Local Education and Training Boards should be informed of the need for changes in formal training arrangements.

*We need to develop learning opportunities to enable the social care and wider workforce to understand issues relating to social care; and then to develop the skills to deliver that social care. The most effective way of building capacity and improving quality is by developing these skills and knowledge. Training is central to this process, but will increasingly need to include a wider variety of approaches: e-learning, blended learning discussion forums, electronic networks, the involvement of service users and carers in the development and delivery of training will all support this activity.*

Cambridgeshire County Council

A number of exemplars were identified by respondents, such as:

- In Hampshire, the Partnership in Care Training team works with care homes which have quality issues to improve standards and practice; courses are mapped to the Qualification Credit Framework and therefore link to the national occupational standards set by Skills for Care and linked where applicable to Care Quality Care essential standard outcomes.
- In Newham, the NVQ Consortium, one of only two in the country, works in partnership with the voluntary and independent sector; it has attracted a substantial amount of European Social Fund money to assist independent social care provider organisations in the borough.

- In Lancashire, the Workforce Development Partnership (a not-for-profit company controlled by the County Council) oversees training and workforce development. The Council argues that effective partnerships such as this can drive up quality in training providers, help make the market in training more secure, help in the strategic commissioning of training for the care workforce and improve dialogue across sectors.

Some respondents argued that quality standards should be incorporated in all aspects of recruitment and performance management and, in the context of self-directed support, promotion of quality in the workforce will require a robust process for accreditation. It was suggested that some individual employers place requirements on members of the 'unregulated workforce' that potentially breach employment legislation and that the workforce must be supported to deal with this. It was suggested that care home managers should be required as a condition of their registration to demonstrate that they receive professional supervision, engage in continuing professional development, and are members of body supporting their professional development.

Hampshire County Council, in its submission, quoted research indicating that the number of jobs in adult social care is projected to grow by between 24% and 82% between 2010 and 2025. To develop additional capacity, the Council suggested that the profession will need to recruit from non-traditional backgrounds, and ensure staff have the skills to meet increasingly complex needs. This will mean workforce planning to ensure the right skills mix, and investment in staff training. As much of this growth will be in personal assistants, at national level there needs to be more support (e.g. through Business Link) for those setting up small businesses, so that people have the legal/financial advice and investment.

## **(ii) Changing attitudes**

The starting point for changing the way social care staff are perceived, it was argued, is to treat social care as an important profession, with a career structure, decent pay and training opportunities. While the profession is underpaid and undervalued as a vocation or career choice, it will struggle to attract motivated staff with the right attitude. The result of annual contract price reviews is a workforce which is typically pay sensitive, characterised by an undesirable "churn" as workers change employers for relatively small increases.

Some respondents argued that to attract and retain care staff with the appropriate skills and attitude will require pay levels above minimum wage. Several commented that the

profession needs to be promoted and valued more highly. The point was also made that compassion needs to be recognised as innate and that training cannot train unsuitable people to become carers.

*Providers, service users and commissioners all agreed that there is an urgent need to change the perception of caring from something that was regarded as a vocation to a challenging and valued career which was well respected and rewarded appropriately.*

East Riding of Yorkshire Council

### **(iii) Workload**

Day-to-day working practices were identified as an issue to tackle:

*Creating a working environment not dominated by crisis work and overload*  
Individual

### **Carers**

In considering the issue of how to equip carers to respond to the challenge of improving quality, respondents made the following points:

- Carers need to have the relevant advice and information so they can make informed decisions
- Carers need to be recognised as key players in social care and listened to
- Carers need support (innovative and cost effective options for this should be explored)
- There should be training opportunities for carers
- Carers should be educated in the changing social care agenda
- Carers must play an active role in shaping and developing local services and should be recognised as equal and expert partners in the design and co-production of a new generation of care services

*The roles of volunteers, particularly carers, need to be given much higher profile and recognition for the significant part they play in direct care and supported self management as the growth in need and demand of an aging population continues.*

NHS Midlands and East

Some respondents commented that *family carers* are sometimes the only people involved in monitoring the quality of an individual's services. It was suggested that this should be formalised by the Care Quality Commission as part of its regular monitoring process.

### **Volunteers**

Some respondents discussed the impact of volunteers on the quality of care services. It was said that although *volunteers* can support care work, and may increase the accessibility of services for more vulnerable or excluded users, without the support, training and management provided by professional paid workers, the quality of provision could be at risk. However, such community involvement in residential and nursing homes helps to improve quality in residential settings.

Several respondents argued that it is necessary to ensure that volunteers are supported with appropriate training opportunities. Others commented that local authority leads and commissioners need to develop a greater understanding of how providers and third sector organisations use volunteers. It was also suggested that councils need to market the role of volunteers in social care and develop a central pool.

*Don't expect volunteers to provide services that were previously provided by paid workers just because of budget cuts.*

Merseyside Employer Led Partnership Leads meeting

### **Leadership**

Local authorities were the main respondents on the issue of how social care leadership could be developed to steer improvements in quality and respond to the expected growth in demand.

There was an acknowledgement that leadership is a major issue within social care at all levels:

*Currently people are trained to manage, but not necessarily to be effective, inspirational and decisive leaders. Training should recognise more clearly the difference between management and leadership.*

Cambridgeshire County Council

It was suggested that social care leadership should be developed by taking a transformational approach, where commitment to a credible vision is widely communicated, owned and clearly acted upon. Leaders need to be in touch with both



the customer and the workforce in order to understand and effectively balance the needs of both and create a synergy. They need to be educated to appreciate the impact and influence they can have in their roles, through on-going professional development. And there should be a creative and business-focused element to their development.

Social care managers also need to lead, and manage, a large, flexible, dispersed and diverse workforce. It was suggested that these issues could be incorporated in a national training programme that distinguishes between operational and strategic management, allowing people to develop and move through the various tiers of management.

*Local managers need freeing up to develop leadership skills.*

*The freeing up of resources by abolishing centrally driven services should be used to enable local leaders to work with users and carers to engage with and tackle local issues of quality, including workforce development.*

British Association of Social Workers

## **Raising concerns**

### **Mechanisms for users, carers and staff to raise concerns about the quality of care**

Raising concerns was an issue which engaged all types of respondents. It was considered an important issue in its own right but also because of the impact on public perception of social care.

Some respondents regarded the mechanisms currently in place as adequate – through whistleblowing procedures, the Care Quality Commission, and local authority safeguarding processes. But most respondents argued that there need to be better ways of enabling people with complaints to feel confident that they will be taken seriously.

It was argued that arrangements for safeguarding practices needed to be simpler, more transparent and more responsive to need. They should not be played down by providers or practitioners ‘dealing with issues in-house’ and therefore not reporting them appropriately.

The main characteristics where there was agreement on all sides were:

- Zero tolerance of poor quality is essential. Individuals must have a voice to raise issues of quality.
- A quality assurance and complaints process, including whistle-blowing, should be in place which should be published by both councils and providers.
- Councils need to make sure the public is aware of the procedures. But they must also manage the expectations of their customers by ensuring that they understand the resource challenges currently being faced.
- Complaints/compliments/safeguarding and care deficiencies reports should be used to improve processes and ensure concerns are addressed appropriately.
- A health and social care ombudsman was suggested as a final resort if local authorities were unable to resolve the issue to the complainant's satisfaction.
- A national Quality Standard would give clients and staff a framework to work within.

Many respondents raised the issue of comparative ratings of social care providers, such as the Care Quality Commission's 'Star ratings' system. While some said it was not flawless, the clear view of most respondents who expressed a view was that it performed a most important function and should be reinstated as soon as possible. It was transparent, clear and needed little explanation to users.

There were mixed feelings about the Care Quality Commission, which was criticised for not acting on, or recognising, complaints; for being behind with inspection; and for publishing non-current data. It was pointed out that its compliance regime serves only to highlight failure and does not recognise or reward excellence. Rating provision as either 'compliant' or 'not compliant' does not differentiate in the level of care being provided or offer useful guidance to older people and their families or commissioners of care.

*A compliant v non-compliant standard is more like a fire safety certificate. It tells you of obvious potential danger but little about quality.*

IPC focus group

Bupa pointed out that in Scotland the regulator has adopted a more 'customer-friendly' rating system: 1-6 across a number of categories. The Australian Accreditation

Agency's Better Practice Awards usefully identify exemplars, and thereby encourage improvements and recognise best practice.

### **Addressing concerns**

There were two things which respondents pointed to with some optimism about addressing concerns. Firstly, a number of respondents were encouraged by the local HealthWatch which will have a pivotal role in improving the mechanism through which users, carers and staff can raise concerns about the quality of care. They must know and understand their local provider landscapes and different needs, so that all groups have the same opportunities to raise concerns.

Secondly, the increase in people choosing and paying for the services they want. People will simply take their 'business' elsewhere if good quality care is not being received.

It was seen to be important that any mechanism must have the support and confidence of all concerned, especially service users and their families, but also providers and the general public, as confidence has been knocked by recent scandals. Several respondents pointed out that people need to be sure that concerns they raise are acted upon - they should always receive a response. And staff need to feel confident that they will not be discriminated against for raising concerns.

*There needs to be a culture shift towards a customer focus and the right for customers to question/challenge and raise concerns and there needs to be clearer and easier routes to raise concerns.*

Newcastle City Council

# **Personalisation and choice**

## Personalisation and choice

### Engagement questions

#### **2. What are the priorities for promoting increased personalisation and choice?**

a. How could we change cultures, attitudes and behaviour among the social care workforce to ensure the benefits of personal budgets, including direct payments, are made available to everyone in receipt of community based social care? Are there particular client groups missing out on opportunities at the moment?

b. What support or information do people need to become informed users and consumers of care, including brokerage services? How could people be helped to choose the service they want, which meets their needs and is safe too? How could better information be made available for people supported by public funds as well as those funding their own care?

c. How could the principles of greater personalisation be applied to people in residential care? Should this include, as the Law Commission recommends, direct payments being extended to people [supported by the State] living in residential accommodation? What are the opportunities, challenges and risks around this?

d. How could better progress be made in achieving a truly personalised approach which places outcomes that matter to people, their families and carers at its heart? What are the barriers? Who has responsibility and what needs to change (including legislative)?

## Changing workforce culture

There was a general acceptance among respondents that a culture change must take place within social care. Some practical ideas emerged from all sides, together with case studies of effective work already taking place. There are barriers and constraints, however, which are noted below.

Four broad themes emerged in response to this issue:

- Winning the hearts and minds of care staff
- Staff training
- Leadership
- Breaking down barriers

### **Winning the hearts and minds of care staff**

The need for staff to really understand what personalisation is all about was emphasised by respondents. A number of local authorities argued that sharing best practice from other councils enables staff to learn from each other's positive and negative experiences. They could be given practical examples of where personalisation and personal budgets had made a positive impact on a service user's or carer's experience of social care. For example, about workers who previously delivered traditional types of care but who now provide a wide range of support, including access to other activities such as leisure.

Several respondents argued that staff who have seen good examples of positive outcomes, or perhaps been exposed to 'champions' of personalisation, tend to become advocates, so giving them the confidence to 'sell' the care package to service users, and finding their job correspondingly more interesting.

### **Staff training**

It was generally acknowledged that for the social care workforce successfully to move from a care management role to a focus on support planning, brokerage, and monitoring of outcomes, effective training is required which then needs to be passed onto service users and carers so individuals can make informed choices. Training, education and sharing good practice can help staff assimilate the behaviours, attitudes and approach to delivery which is necessary for delivering personalised services.

Because caring skills are to do with attitudes not just qualifications, a number of carer and user representative groups pointed to the importance of involving service users and carers in the training, to harness their knowledge and expertise in the field. This could include workers spending time with the service users to understand the differences in their requirements - shopping, transport, financial management, and managing personal assistants, as well as everyday tasks such as cooking, cleaning and washing.

One suggestion was for regular focus groups of service users, carers and staff so that, as they learn from each other, a more imaginative culture could evolve, breaking down 'us and them' problems and facilitating 'circles of support'. This, it was argued, would need more resources being invested in community development, but it would be 'money well spent'.

*Social care staff need to be trained with a top down approach by service users about the issues that are involved in personal budgets and how they affect the service users.*

Gateshead Access Panel

## **Leadership**

Leadership of all kinds – clinical, citizen, community – was identified as necessary to help staff buy in to the changes. Leadership teams needed to embrace new person-centred ways of working internally, with providers and other third sector organisations, as well as with service users and carers. Leadership was also seen as important politically, nationally and locally to lead a culture change – for example through a national campaign to bolster the reputation of the care workforce, so that they become trusted by their customers.

*People [who are in charge of introducing personalisation] ... in many cases simply do not understand the pressures on families of people with learning disabilities.*

Carer

## **Breaking down barriers**

It was argued that a number of practical barriers would have to be removed if a cultural change is to take place. Non-statutory agencies tended to say that the problems lay with local authorities rather than the workforce. Several commented that there was insufficient funding to ensure that personal budgets meet basic needs in an increasing

number of cases, together with a reluctance to encourage direct payments, given the extra administrative burden. There was also a reluctance to allow individuals full freedom to choose their own support solutions. Authorities were accused of not taking forward the development required for their staff. And staff were said to be too simply busy to be able to focus on the new agenda:

*Our experience of personalisation suggests it is not the cultures, attitudes and behaviour of the social care workforce which needs to change, but the cultures, attitudes and behaviour of local authorities.*

United Kingdom Home Care Association

It was also suggested that staff were unsure of the extent of their legal responsibilities when clients chose to organise their own care. Some respondents talked of a culture of blame in social care which creates risk aversion. Staff need the confidence and skills to make a decision for their client without fearing unfounded repercussions.

*Part of [workers'] 'fear' could be eliminated by raising the professional profile of social care staff and promoting positive media images. Central Government should take a lead on this.*

Surrey County Council

It was argued that this has led to an unwillingness to allow people the freedom to choose and manage their own services. Implementation of the Law Commission recommendations would therefore be helpful in ensuring that the legal framework supports personalisation: for example, by clarifying the duty to assess, the status of self-assessment, and the duties of the local authority relating to safeguarding. Staff would then be clearer about the extent of their legal responsibilities.

A couple of respondents pointed out another practical issue which needs to be addressed is that the workforce could end up with several employers, leading to concerns about tax and pension rights.



## **Client groups missing out**

One of the main excluded groups mentioned were older people, who perhaps do not see themselves as in need, 'just getting older...'. Some respondents argued that older people are often not keen to take on more responsibilities and could be reluctant to take on the role of employer. It was suggested that dealing with this would require a gradual process, built up through established mechanisms for advice, support and protection, reinforced by peer group contact and learning.

Other excluded groups mentioned were:

- People with mental health experiences including dementia.
- People with sensory impairments (deaf and blind).
- People who qualify for Continuing Health Care Funding. The most marginalised people tended to be those with the most complex needs such as a profound or severe learning disability, or a long-term and enduring mental health issue.
- People with language difficulties (including immigrant communities) and others with profound communication difficulties.
- People in shared and communal housing, where issues around tenancies can take precedence over personalisation.
- People nearing the end of life, where in fact the view of the National End of Life Care Programme was that personal budgets hold out much potential for resolving problems of lack of continuity of funding which cause disruptions in care.
- The Prison Reform Trust noted that the situation regarding prisoners was unclear, adding that '93% of prisons did not have social service involvement'.

Plans can be relatively complex and user groups were concerned about the risk that anyone apart from the most articulate could be excluded because of this complexity. For some people with learning or mental health difficulties, support is required but many carers were said to be under massive pressure – without the time for the paperwork, and they get stressed and ill themselves.

Some respondents argued that to assist these potentially excluded groups, advocacy and brokerage services would be required, together with support from commissioners

to develop a choice of service providers, to ensure that personalisation would not be limited to the most informed.

*In common with most councils, people who lack capacity and those with dementia are under-represented in the overall numbers for those in receipt of personal budgets.*

London Borough of Barnet

## Support and information to become informed users

Respondents of all types identified support and information as critical for the successful implementation of reform and, although there was seen to be good practice in some areas, for the most part they acknowledged that there was a serious need of improvement.

*Information is the key: vulnerable people can only exercise choice and their right to personalised solutions if the options are presented to them in ways and formats they can truly understand.*

NHS Blackburn with Darwen

### The challenge

Despite information being available on the internet, at information hubs such as Citizens Advice Bureaux, and a range of leaflets and video-based resources created by different groups across the sector, there was a general concern that information is fragmented and unfocused. In its submission, Which? reported that in 2008, only one in ten people who had been involved in an older person's care found it very easy to get information to help them make decisions, whereas four in ten had problems. A 2011 survey indicated that finding information and advice was the third biggest concern for people when thinking about long-term care. The majority of respondents to their survey had relied on advice from local authorities, but Which? said that such advice performed worse on all counts of quality compared to other advisors.

There was a general acknowledgement in submissions that information on personalisation was uncoordinated, yet it was critical that potential users and their families have reliable, detailed and fully independent information, coupled with a measure of support and guidance, particularly for people who lack capacity. Each local authority's particular priorities and markets mean that there is not always consistency in

the information given. A further problem was that often people only seek information when they are faced with a health/social care crisis, or were in need of care. Leaving the decision to purchase care until a 'critical crunch point' such as a hospital visit has meant that many do not feel confident in the decisions that they make.

*Rarely does someone sign up to a service of which they have so little knowledge.*

TLC Group

### **Main information needs**

Respondents' views on where support and information are needed covered the whole system and the whole pathway – from information about how to stay as independent as possible and how to access social care if needed, to the quality and costs of specific services to help service users make the best decisions based on their available resources.

It was argued that the right level of information and support has to be accessible, particularly to the most vulnerable, so that they better understand their options, appreciate the benefits and risks of their choices, and are supported to make personally relevant decisions that result in the best possible outcomes. A number of areas where specific information was required were identified by respondents:

- **Personal budgets:** A number of respondents felt that the process of personal budgets could be intimidating and there needs to be sufficient support in place to guide people through the process.
- **Comparing services:** Service users should be able to compare services by price and locality. Care managers and key workers need to gain knowledge and confidence around personalisation in order to be able to accurately advise.
- **Employment issues:** Service users need better information and advice on their responsibilities as employers, to manage budgets, tax and national insurance, and the safeguarding issues of employing a personal assistant rather than an agency.
- **Finances:** Respondents identified a gap in service provision for those needing practical support managing finances, especially for those with dementia or mental health problems. The Surrey Care Association suggested that issues regarding safeguarding using the Mental Capacity Act 2007 needed to be fully incorporated into all direct payment schemes so anyone acting on behalf of a person who lacks capacity to manage their finances is monitored.

- **Equality issues:** The Equality and Human Rights Commission reported that, unless adequately supported, certain protected groups (under the Equality Act 2010) may be unable to benefit from greater choice and 'personalisation' in the social care support they receive. Feedback from a consultation event with women carers from Muslim backgrounds was that they were often not aware of all the help that is on offer: there were many agencies and people to deal with and it could be very confusing for someone who does not understand English. And specific groups reported problems such as that from the Royal National Institute of Blind People which commented that seven out of ten blind and partially sighted people reported that personal information they were given from their GP had not been in an accessible format.
- **Critical diagnosis points:** Cambridgeshire County Council's dementia review findings highlighted the need to improve access to information and support around the time of diagnosis. Service users and carers needed information about the condition and how to deal with it, or the support and services available – partly because, the review found, GPs and other professionals did not always know themselves.

### **Sources of information and support**

The main challenge respondents felt about current information and support was that it is uncoordinated. The clear view was that everyone should be made aware of what services are available no matter who provides them so that, whatever channel is selected, the information they receive is accessible, accurate, up to date and consistent. Respondents agreed that there needs to be a wide range of support, in a format and media that meets needs and preferences, with complementary messaging from public, private and third sector organisations.

A number of 'ideal' characteristics of these channels were identified:

- Information should be **proactive**, i.e. promoted to service users or potential service users, families and carers, earlier rather than at crisis point.
- There needs to be national **consistency of terminology**, for example 'personal budgets' or 'individual budgets', to avoid confusion; all information should be user-friendly with no jargon, acronyms, or abbreviations.
- Rollout of the e-marketplace, such as that being piloted in Doncaster, would be particularly valuable if introduced with a **nationally recognised kite marking** of accredited or quality services.

- Information for self-funders and people on state funded care should not be different.
- There should be **a rating for the service** which users have received.
- Local authorities could take a strategic role in monitoring support and information arrangements.
- Information should include concise, 'slice of life' **case studies** where people can identify with the story teller to understand better how personalisation can help, particularly for those people who experience communications issues.
- **Appropriate communication support:** for visually impaired people, for example, this would include a British Sign Language interpreter or a speech-to-text reporter to be provided where spoken information is being communicated, and any written information should be provided in British Sign Language clips and in plain English.

The main information channels identified by respondents were as follows:

*(i) The internet*

- The key would be to have effective and accessible information on the internet, direct for example from the local authorities, which is up to date, easily accessible and of excellent quality. Although there are still pockets of people in deprived areas and the very old who are not comfortable with or able to access the internet, it is important to have publicly accessible databases that are intuitive to use and carry relevant information.
- Web-based real-time information could be used to enable service users to prioritise and take control of the activities they need to buy to achieve their goals.

*(ii) Advocacy and brokerage:*

- Included as part of the person's individual budget could be a sum earmarked to pay for the services of an advocate, a circles facilitator, care co-ordinator, person centred planning facilitator or some other kind of support aimed at assisting them in organising reliable care on their own behalf, writing and reviewing support plans, or ensuring that the support the person receives matches their desired outcomes. By having control over exactly who advocates on their behalf, rather than being tied to a single local authority funded advocacy service, the person can choose people they know to be effective and trustworthy to assist them in holding their service provider and other parts of the

service system (including the local authority) to account. People could also agree to pool this money in order to gain collective representation, including legal representation.

*(iii) User networking*

- Communities and families can offer an informal network of knowledge and resources to support informal methods of brokerage. This needs to be valued, while still recognising that local authority social care staff are also well placed to adopt the roles of specialist in-house brokers. User-led organisations can offer peer support, positive role models and advice about safety and risk. Funding third sector signposting and support services would help to bridge some of the gaps in information for budget holders and self funders.

*(iv) Written materials*

- Information should be concise and mindful of the readership's needs in terms of language and disability. One important need would be a serviced directory with what is available locally and details of all who are on any framework agreement.

*(v) The media and campaigns*

- TV media could disseminate information on care and health through soaps for example as an effective way of reaching older people.
- A national awareness-raising campaign would be useful, with third sector involvement, setting out how to access social care, especially in time of crisis. This would increase understanding amongst the general public, as well as immediate potential users and carers and their families. However, it was noted that one-off campaigns have most value when reinforced with on-going support.

*(vi) Social care and health staff*

- GPs could be an appropriate point for signposting, as often they are the first point of contact for someone who may require social care support. However respondents reported varying experiences. Some commented that GPs and other frontline health workers, for example based at A&E, do not understand social care services or other organisations that can meet their patients' needs.
- Social workers were identified as a key source of information and support although many people paying for their own care were not supported by one.

(vii) *HealthWatch:*

- Respondents were generally optimistic that independent, local HealthWatch bodies had a key role to play from October 2012 and argued that they should be adequately resourced.

(viii) *First stop shops.*

- Respondents felt that, since its inception five years ago, FirstStop Advice has effectively brought together specialist agencies from the voluntary, statutory and commercial sectors to deliver independent advice and information for older people. There was general agreement that there is potential to build the FirstStop model further through promoting and celebrating examples of good practice.

*We recommend that Government – DH, DCLG and DWP, with other Government departments as appropriate – work together to build on FirstStop.... Statute should ask that councils ensure the provision of information, advice and assistance, rather than being expected to provide it.*

Housing and Ageing Alliance

In summary, the over-riding message from respondents across the board was that there would be no quick fix to the communications challenge. The need was identified for new channels of information, advice and advocacy systems that draw upon the experiences of people who have first-hand experience, including peer advocacy services and user led organisations. In any event, different people needed different channels:

*All the advice websites and telephone help lines in the world, will be of no use to the majority of elderly people, who really need personal help and support to ensure that they make the right decisions about such a critical aspect of future health and wellbeing. We are really concerned that there is a direction of travel away from personal help and support towards advice*

*lines. In our view this is short-term cost saving put ahead of doing what is right and ensuring long-term best use of*

resources.

Mears Group PLC

## Personalisation and residential care

### Applying the principles of greater personalisation to people in residential care

Most respondents favoured applying the principles of greater personalisation to people in residential care, assuming the resource allocation system could be amended to facilitate this. There were a relatively small number of people who urged that caution.

The predominant view from this engagement, from all sectors, was that the type of care should have little bearing on the principle of personalisation.

*Risk to my independence, and my vulnerability, to independence defines the personal offer of support, not where I live. Being in a residential setting should not matter.*

North Yorkshire County Council

*Definitions of how care is provided, e.g. domiciliary, residential, supported living etc, are often misleading and historically-based. Care should be seen as a continuum, and the same principles in respect of funding should be used for any service user. Support should be available to anyone.*

HC-One

The general view was that personal budgets in care homes would uphold the principle of choice for people: some submissions referred to a Demos report (*Tailor Made*, Claudia Wood) which used the phrase 'personalised approach to personalisation'. Residential care homes could be encouraged to develop a greater range of personalised support for their residents – a menu of services – including where necessary one-to-one support, rather than generic support. These could be purchased flexibly via an individual's personal budget allocation, thus separating charges into accommodation, personal care and activities. Day-time activities, entertainment, or opportunities to build skills and engage with society outside of the residential home, could also harness more community involvement with residential homes.

Possible barriers identified were generally in the spirit of caution rather than opposition to the principle of personalisation in residential care. A care home provider, for



example, argued that time was the enemy of personalisation – there was not enough of it:

*Time is the element required to make better progress in truly achieving a personalised approach - something that we seem to have so little of on a day to day basis. The inability to provide higher staffing levels due to staffing costs and poor fee levels are the barriers in this situation and this should be addressed at national and local levels.*

Merafield View Nursing Home

And the British Association of Social Workers judged that the proposal would need to be piloted and evaluated:

*There is a danger that imposing a structure of individual budgets will get in the way of personalised care in a residential setting. If personal budgets are to be tried in residential care, it is essential that it is properly piloted and independently evaluated, with attention also given to the impact on people who are not on individual budgets. The true transaction costs of introducing a potentially more complex system also need to be included in the evaluation.*

British Association of Social Workers

Respondents were concerned that care homes may not be able to provide a range of services for patients under the same roof (although perhaps pooling arrangements might alleviate this). There was also the question of who manages the personal budgets, which many older people in residential care might find quite complex if family carers were unable to take on that role. One respondent queried whether funds allocated for people in residential accommodation might be misappropriated.

Stonewall pointed to the challenges already faced by gay and lesbian residents who often fear discrimination in care homes and that personalisation will make it all the more necessary for the Government to set out a way forward for improving all residential care across England to respect dignity, human rights and diversity.

For some respondents, personalisation in residential care would highlight the need for safeguarding and the publication of quality standards. Residential accommodation

providers would need to be held to account for how they ensure that residents are able to exercise choice and control. But the overall message was clear:

*We need homes fit-for-purpose for the twenty first century. They need to feel they have stake in the future. The role of care homes, as part of the whole narrative on care, needs recognising by the policy centre. Personal budgets should give people choice across the care spectrum, whether that care is in their own home or a care home setting.*

Lancashire Care Association

### **Extending direct payments to people supported by the State living in residential accommodation**

Fewer respondents commented on the Law Commission recommendation that direct payments should be extended to people supported by the State living in residential accommodation. Respondents were much more cautious about this compared to the general principle of personalisation, particularly among local authorities.

On the one hand, it was argued that direct payments would increase choice and control and support the fee negotiation process. People may be able to choose other settings for short breaks or to purchase care at home, which may make providers more customer-focused.

*The barriers [to direct payments in residential care] can be overcome and should be an aspiration for all as the opportunities that come with increased choice and control are huge.*

Turning Point

Local authorities, in particular Kent and Staffordshire County Councils and Bury Borough Council, argued that there are alternative ways of offering greater personalisation to people in residential care, such as having a greater say in care regimes, activities, staff rotas etc (co-production) and involving the outside community more. This could be supported by a Health and Social Care commissioning strategy, making it one of the marks of quality considered by the Care Quality Commission. The councils set out a number of challenges to the introduction of personal budgets:

- A resident may not have capacity to manage money, so there would need to be safeguarding arrangements in place if a representative is to do this.

- Residents may find they are charged the private (usually significantly higher) rate and are not able to access the local authority rates: they would not have the bulk buying' power of a local authority.
- Residential care is often needed at a time of crisis. Individuals or carers may not have the capacity to enter into arrangements with care homes.
- Direct payments could result in less protection for individuals, so they must be offered the same protection as other local authority funded residents, i.e. subject to regular reviews of their needs.
- Reduced income for the residential home may lead to a reduction in the quality of the service:

*Direct payments should not be extended to residential care as the process is onerous, time consuming and will not provide service users with an increase in choices. The choice directive which service users currently have should remain (choice of which residential care home they wish to go to).*

Durham County Council

*One of the points of residential care is to provide economies of scale for more intense levels of support and this would not be achievable if people had true choice in who provided it. This is already the case in extra care settings. The use of direct payments in such cases would smack of tokenism.*

Newcastle City Council

## Making progress with achieving true personalisation

This issue engaged respondents a great deal, with no great differences of view emerging across sectors. Respondents spoke of the need for a ‘culture shift’ from people requesting ‘services’ to arranging ‘support’, for which primary responsibility rested with local authorities.

*There seems to be a disconnection between ‘want’ and ‘need’ – the language of self-directed support is all about ‘want’, and ‘aspiration’ but the legal context and reality of adult social care is meeting ‘need’.*

Newcastle City Council

Social workers (‘gate-keepers’ in the care management model) were seen to have a key role in communicating directly to individuals and helping people come up with their own personal solutions. They also need to work closely with universal services to ensure compatibility with a persons' care and support needs to provide a range of services such as leisure, transport and generalist ‘home help’ services in addition to their traditional care services. Staff who have time to work alongside service users to develop support plans and care packages, should improve and promote the perception and reputation of personal budgets, but they need to be given the confidence to take this forward:

*[We must give] social workers and other professionals permission to be able to develop and act professionally.*

British Association of Social Workers

Several respondents raised the issue of the importance of timing, as people often think about their needs only at a point of crisis. This means there needs to be an awareness of personalisation from the outset and at all stages in a social care assessment, not bolted on at the end.

Many respondents argued that service users or potential users, along with their families and carers, should be at the centre of designing and having control over all decisions that are made, in order to shape their life in a way that meets their needs and suits their own circumstances. Democratic structures that include service user forums and panels can ensure users are more actively engaged in influencing policies and practice in partnership with staff. This can be supplemented with case management and risk profile management for those with the most complex needs so that informed

professional input supports and monitors the outcome of the less formal care delivery package in terms of quality and value for money.

*Ask individuals what support they think they require to maintain their independence and test this against a value for money criteria i.e. is this reasonable and is this affordable? If the answer to both is yes then ask the individual how they would prefer this care to be delivered; either by a member of their extended family/community/voluntary sector or a paid professional. Once individual preferences are identified packages of support can be negotiated with the preferred supplier/provider.*

Leeds City Council and Leeds CH Trust

Most agreed that a framework would be necessary whereby organisations can check their progress and decide what they need to do to deliver real change and positive outcomes (a developed form of the Think Local Act Personal group's 'Making it Real' framework). Proper use of the support planning process, where individuals state what is important to them and, then, capturing at review the extent to which these outcomes have been achieved, would help make this a reality. All partners and agencies need to be involved in reviewing people's outcomes to give an element of objectivity. Such a clear focus on outcomes does not yet always happen.

There was general agreement that there should be more emphasis on the role of advocacy and the use of health and social care coaching by all front line staff. Advocacy, it was argued, is often best delivered by other users, for example by disabled people for disabled people, because they have direct experience of the barriers that prevent people from living independently and exerting choice. Advocacy should operate holistically across health and social care sectors, taking into account other relevant considerations such as housing and transport.

*The right to advocacy should be enshrined within the law ... so that public bodies become more aware of their obligations under the Human Rights Act.*

Breakthrough UK

Finally, a number of respondents argued that it had to be made clear that personalisation was going to happen – *'to end the myth that personalisation is optional'* (East Riding of Yorkshire Council). It was said that the problem with introducing more

personalisation and choice at a time of budget constraint is that these terms generate greater expectations. Realistic messages need to be communicated nationally on this issue, and the expectation that families and communities take more responsibility themselves. This is a role for Government. But personalisation also needs champions, both from within the new structures and from user groups and individuals who have experience of personalisation. Other devices included using successful case studies and developing a bank of evidence-based practice. Information would be key, not only on outcomes and processes, as discussed elsewhere in this report, but also on how much social care costs: this, it was suggested, might encourage people to access care early rather than find themselves in crisis later on and consequently needing more support.

*The overarching consideration when debating how we can achieve a truly personalised approach, which places outcomes that matter to people at its heart, is the individual's right to quality of life measures, rather than the traditional focus on, and performance measurement of process.*

Bury Council

### **Barriers to achieving personalisation**

Respondents most frequently identified **service users' attitudes** as the main barrier to progressing personalisation. Service users' groups and local authorities acknowledged that some people just do not want choice. They may get anxious at the prospect, for example, of having to choose the right people to care for them – including family members, where there may be worries about abuse – and of the responsibilities of employment. The administrative burden of personalisation is an issue for some:

*I care for my mum who has dementia.. I neither have the time or the energy to take this on...hiring and firing, police checks, financial management....Who would monitor all these personal budgets to ensure safety for all involved? I can see huge sums of cash disappearing!*

Carer

Some were sceptical of the Government's motives for the introduction of personalisation and were worried about their ability to fund essential services. This links with the lack of **information** and sound, consistent advice to make an informed choice about future care. Without better communications, more support for families and

service users, and independent advocacy and brokerage, the potential for personalisation to transform the experience of social care will not be achieved.

*I would have problems with receiving a direct payment. This would essentially make me someone's employer and I definitely do not want or need the extra additional responsibility because it would add to my anxiety levels.*

Service user

**Staff** have a clear role in dealing with these attitudes. But local authorities acknowledged that they have in the past focused disproportionately on process rather than wider developments that are crucial for choice and control, so user benefits have not always been apparent and some staff have become sceptical about personalisation. As has been discussed earlier in this chapter, there is therefore seen to be a need for a cultural change among staff and providers so that they develop more flexible responses to service users' needs. Knowledge also needs to be improved. Bury Council, for example, pointed to the misconception that Continuing Health Care funding cannot be given through a direct payment, which results in packages being fragmented. It suggested that this should be dispelled given the options to ensure that the service user has a holistic package.

*The key barriers to personalisation are the staff working within the statutory sector. Personalisation can be threatening to individual feelings of power and control for social care staff.*

Disability Cornwall

A number of local authorities commented that a major barrier has arisen from **cuts in grant funding** and pressures due to demography and increased complexity of need. For example, currently Ordinary Residence presents barriers to moving to community-based living arrangements, particularly for people with learning disabilities, as the de-registration of residential homes can lead to significant financial liabilities for local authorities dealing with out-of-county clients.

Another example was that personalisation could be stifled in day services as more traditional approaches (with fixed timings etc) may be more cost effective than a series of individualised and personalised services. Authorities argued that the public sector, working with business, the voluntary sector and community based organisations, must find innovative and flexible ways of dealing with these financial challenges.

*We need to recognise what is feasible e.g. true personalisation could mean that, given the choice, many people would prefer to have treatment (and care) at home. This would have massive resource implications.*

Middlesbrough Council

*As councils continue to manage budget reductions, it is likely they will be forced to ration provision further, tighten eligibility criteria and extend or increase fees and charges, all of which are likely to restrict service user choice.*

Society of Local Authority Chief Executives (SOLACE)

Social care provision can also be affected by budget cuts in non-social care services such as the availability and affordability of transport to and from social care in rural areas. The Commission for Rural Communities argued that this was compounded by the lack of choice of providers in rural areas, yet predominantly rural local authorities receive smaller funding allocations for social care from Government, per capita.

*The cost of delivering services in rural areas is inevitably higher ... because of travelling distances and the smaller economies of scale.*

Commission for Rural Communities

The need was identified for the public sector to **facilitate and promote the development of a wider range of services**, by working with service providers, and using the contractual process to bring about change. The impact of size of provider on the market was a moot point among respondents. While it was argued that there are too many small providers and not enough range of services provided by each one, more respondents were concerned that user-led organisations were being disadvantaged by tendering and commissioning practices and were losing out to large national organisations. The latter, respondents argued, cannot provide the personalised support needed. There were also particular concerns expressed about the market for specialist provision.

*There is limited availability of person-centred services... making it harder for service users, particularly older people, to raise their own expectations of what they could receive.*

Cambridgeshire County Council



Regulation of the market to ensure it is safe and appropriate has the potential for stifling the market in terms of choice, control and flexibility. A user-group representative argued that there were still far too many restrictions placed on service users to enable them to use personal budgets flexibly. The balance between safeguarding, being accountable for public money, and allowing service users choice and control to pursue personalised outcomes with personal budgets was seen as difficult to get right.

*Many practitioners and their managers still do not understand the principles of self-directed support enough to put them into practice.*

South East Network of Disabled People's Organisations

Finally the legislative context was challenging in many ways for personalisation. A number of respondents felt that the application of Fair Access to Care criteria leads to the prevalence of crisis decisions, limits 'personalisation', and maintains a confused state of social care. The rhetoric about personalisation, it was argued, was at odds with the low level of safety net. If it is only possible to receive support when they are designated as 'critical', a service user's choice and control over his or her life will be extremely limited. There was support for the Law Commission proposals for untangling current legislation and to clarify boundaries and concepts, including freeing up money in the NHS.

Respondents generally did not specifically address the question of responsibility for personalisation. However, the tenor of their comments did not shirk their own responsibility for supporting and facilitating personalisation, while also noting the responsibility which by definition lies with users and Government.

As for what needs to change, respondents for the most part were content to allow their earlier comments to speak for themselves. The need for information, advocacy, joined-up action on many levels, equality of opportunity, regulation of personal assistants, and the importance of user-led organisations, were all reinforced. Similarly, the value of the Government publishing guidance on applying the rules on Part B procurement, framework arrangements which would enable a local authority to adopt a flexible approach, and an evaluation of the Social Work Practice Programme pilot were also discussed. One comment in particular chimed with a thread through submissions on personalisation – the need for a strong market:

*The Government's vision for personalisation cannot become a reality without a vibrant care market which delivers genuine*

*consumer choice on a variety of services ranging from telecare to low-level preventative support and specialist services for people with complex needs.*

Carers UK

# Integration

# Integration

## Engagement questions

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

- a. What does good look like? Where are there good practice-based examples of integrated services that support and enable better outcomes?
- b. Where should services be better integrated around patients, service users and carers – both within the NHS, and between the NHS and local Government services, in particular social care (for example, better management of long term conditions, better care of older people, more effective handover of a person's care from one part of the system to another, etc)?
- c. How can integrated services achieve better health, better care and better value for money?
- d. What, if any, barriers to integration should be removed, and how can we incentivise better integration of services at all levels?
- e. Who needs to do what next to enable integration to be progressed in a pragmatic and achievable way?
- f. How can innovation in integrated care be identified and nurtured?

## What does good integration look like?

There were no real distinctions between the views of respondents from different sectors. But there were two issues which characterised most responses. First, good integration is person-centred. It is about systems which work together with the individual in mind. Second, it is about outcomes – where people and organisations work together with shared objectives in mind, not about tasks and structures which are simply means to an end.

More generally, respondents' perceptions ranged along a continuum in terms of complexity, from a relatively straightforward definition of people working together to a much more sophisticated model of whole organisations and budgets being combined. And all points in between these extremes were identified by different respondents.

The continuum is imperfect because there are a large number of variables which can impact on the definition of integration – departments, organisations, different services, budgets, and so on. However, it is a useful device for illustrating the breadth of respondents' understanding of the expression 'good integration'.

Four respondents used pre-existing definitions of 'good integration' which in summary were:

All Party Parliamentary Group's report ('Please Mind the Gap: Parkinson's disease services today 2009): *The key components are: integrated multidisciplinary teams built around the person's needs; professionals with a good understanding of the condition; services joined up around the needs of the individual with effective communication; the information needs of people are met on all aspects of living with the condition; and support for carers through breaks, emergency planning and services that address their physical and psychological needs.*

Parkinson's UK

Report of a Working Party of the Royal College of Physicians, the Royal College of General Practitioners and the Royal College of Paediatrics and Child Health: London, 2008: *Teams without walls: the value of medical innovation and leadership.*  
Royal College of Physicians and the Royal College of General Practitioners (separate submissions).

World Health Organisation, 2008: *For the user, integration means health care that is seamless, smooth and easy to navigate. Users want a co-ordinated service which minimises both the number of stages in an appointment and the number of separate visits required to a health facility....In short, clients want continuity of care.*

NHS Confederation

National Voices' Principles of Integration: *We support National Voices' Principles of Integration and the emphasis on assessment and services focused on user and carer, measured through shared outcomes and based on the core principle that users/patients and carers are at the heart of any commissioning or provision across health and social care.*

Standing Commission on Carers

(i) The most basic type of definition put forward by respondents themselves was simply that the user is happy, in which case, it was argued, integration is by definition in place:

*Happy, healthy and comfortable service user.*

Living Options

*'Good' looks like satisfaction in a small way.*

Asante Cultural Forum

*'Good' is when the patient is happy and relaxed with the care he/she receives.*

Individual

(ii) The next step along the continuum is for respondents to talk of working effectively across boundaries in order to create a user-focused outcome:

*Co-ordination of separate resources into a shared outcome, whether this is combining funding streams; sharing and assigning the same outcomes across multiple different staffing teams; or getting rid of barriers in the commissioning process that separate different sectors (health, housing, social care) from working as one larger team.*

Turning Point

*All organisations working together – health and social care but also housing, leisure etc. – to plan services, to commission services, and to monitor quality.*

Individual

*People working together effectively across boundaries and without bringing to bear their former professional allegiances or putting assumed barriers in place.*

Royal Borough of Richmond

(iii) Then the definition goes beyond the act of working together to become focused on outcomes, where tasks and organisations become secondary, and where systems and communications are designed with joint objectives rather than disparate ones:

*'Good' is the seamless provision of a service across health/social care/third sector, with information held about the individual in one electronic file, accessed by those who need to have the information.*

Middlesbrough Council

*'Good' looks like services that are aware of each other, know what other support and follow-up are available for patients, and have a good working relationship with other services to ensure transitions are smooth. Patients' needs are communicated between services, with no need to repeat themselves to different health or social care professionals.*

Plymouth LINK (Local Involvement Network)

(iv) Then we move up to people and organisations working together in a more sophisticated way, with a clear focus on outcomes and the user, with single points of reference for the clients, sharing some budgets, and organisational and personal interests submerged by clear and common shared objectives.

*'Good' is care pathways developing across health and social care, patients experiencing a seamless and personalised care package, ... with a focus on the individual as opposed to organisations, services or professional disciplines.... The emphasis should be on defining the outcomes to be achieved by the health and social care system, with choices about the*

*means of integration a matter for local decision.*

Barnsley Council

*Really good person-centred planning... with multi-disciplinary professionals working productively together involving disabled people and families... Communication between services and information sharing.... Celebrate and share good practice.*

Yorkshire and Humber Network of Family Carers

*'Good' integration is a localised structure with a national care record. A clear and unilateral understanding of local needs should form the foundation of our approach, as partners in social care and health. This should be built upon with, at the very least, integration of information technology systems and holistic inter-organisational awareness. There are four key areas: pooled funding agreements; information technology; common understanding of local need and clearly delineated responsibilities.*

Bracknell Forest Council

(v) And at the end of the continuum, total integration, where organisations and budgets merge, there are no interests to get in the way of meeting common objectives.

*Ideally a single organisation should have responsibility for meeting all health-related needs including those related to age. GP surgeries might be an access point for support that did not require hospital treatment or medication. City-wide services such as equipment and adaptations could then be accessed via this point and individuals could refer themselves for support providing the need was related to health.*

Partners for Inclusion

*'Good' looks like services that put the patient/service user at the centre and wrap around them in a truly integrated seamless way. This would include a key worker/ case manager, integrated health and social care practitioners, a single set of records and integrated IT system. Services would be accessed only through a single point of referral supported by clinical navigation. The philosophy of care would be based upon co-*



*production and co-design, maximising the patient/service user's ability to self care and have control over their care and how this is delivered.*

Leeds City Council and Leeds CH Trust

Some respondents effectively opted out of the discussion by saying that 'good integration' will have different meanings for different people. The only important thing which matters in the end is how the client would define it:

*There is no one single model of integration that will be fit for all elements of social care.*

St Helens Council

*'Good' should be defined by the customer and be based on meeting needs and outcomes.*

Rotherham Metropolitan Borough Council

*People know what 'good' looks like for them. Services too often set their standard of excellence without regard to the people & families using them. Integration would be simpler if all services focus on the end user's outcomes (working collaboratively to meet those) and not their own targets or ambitions.*

Inclusion North CIC

For the most part, respondents did not discuss efficiency in their definitions of 'good integration'. They focused on the outcome for the client. Clearly the definition has a different dimension when efficiency and value for money are also brought into play. Better value for money, *and* outcomes being achieved, means that potentially savings can be used to help other people.

*Good is where we have co-produced outcomes that enable people to lead the lives we are capable of and the professional boundaries of staff don't impact on the individual but rather support a seamless approach. Good is also where there is value for money and where long-term costs to the state are reduced. This is important because it frees up resources for prevention.*

Kirklees Council

The final dimension to consider is the *extent* of integration. Some respondents distinguished between vertical and horizontal integration and identified a wider breadth to integration, going far beyond the limits of just health and social care services. A theme from many the submissions is the issue of housing which, it was said, can get overlooked in discussions of personalisation and integration but, as a number of housing submissions observed, the role of housing is key not just in terms of the social care system but also as a way of avoiding the need for the care system for some people.

*There is an important role for housing and housing-related support services, working creatively and collaboratively with our partners to meet and exceed people's needs and aspirations, alongside financial inclusion, access to education, training and employment, and environmental factors such as noise pollution and exposure to green space.*

Gentoo Group

*As well as the NHS, social care and public health, a truly holistic, integrated support system for vulnerable people also includes consideration of community services (for example, libraries and churches), local transport facilities, leisure facilities (including parks), education opportunities and policing (with many older people in particular having issues about safety in the community, and many people with mental health problems and people with learning disabilities being the victims of hate crimes).*

Mental Health Foundation

But, as the British Association of Social Workers observed, ultimately there can be no such thing as pure integration. There will always be boundaries. Integration should not equate with role ambiguity, rather the importance of a range of professionals should be recognised. Shared values objectives, 'constant vigilance about outcomes', it was argued, can transcend actual integration.

*Bringing services into the same organisation or under the same manager does not of itself make them work better together. But shared values and genuinely shared goals can.*

Individual

*The key to improved integration is a joint commitment to a shared set of priorities, alongside mutual trust and respect. Joint working can continue irrespective of funding and management arrangements.*

Stockton Borough Council

*Full scale integration around patients, customers and carers is not always appropriate. It would be better to concentrate on co-locations, effective referral mechanisms and joint funding for individual care packages where appropriate.*

Bury Council

*It may well be that formal integration does not occur. One of the problems of integration is that there are always going to be boundaries with other services. For example if health and social care are integrated, then housing and community services are likely to be a boundary, similarly adult and children's services....The fact of integration doesn't mean that there is no inter-professional or intra-professional rivalry. The key is constant vigilance about outcomes for service users and carers/patients, so that pathways run seamlessly.*

British Association of Social Workers

## Examples of Integration

A number of examples of practise-based evidence and instances of integration were submitted by respondents. They are set out below; more details are available on many of them in respondents' submissions.

<p><b>Age UK:</b> Torbay Care Trust has pooled budgets and appears to be having success in both outcomes and reduced admissions. Also adapting a medical team so that, rather than being limited by specialisms, they are more effective at tending to multiple needs, as in Ashton Leigh and Wigan Hospital.</p>
<p><b>Arthritis Care:</b> (i) Torbay Care Trust is a good model which may well be fully replicable in many other parts of the country. (ii) Pennine MSK Partnership (iii) Brighton &amp; Hove Integrated Care Service.</p>
<p><b>Barchester Healthcare:</b> (i) Many POPPS (Partnerships for Older People Projects) schemes which freed up budgets for co-operative work between health and social care agencies (often designed to prevent or shorten hospital admissions). (ii) LinkAge, which bought together networks of independent providers to prevent duplication of services and promote inter-agency signposting.</p>
<p><b>Birmingham Advisory Council Of Older People:</b> In the modern care settings in Birmingham's extra care &amp; care centres</p>
<p><b>Bradford Strategic Partnerships:</b> (i) Learning Disability Services, where the landlord and service provider were disaggregated. The support service has been able to provide advocacy and improve accommodation for the person with a learning disability. This has led to greater accountability and tenant empowerment, e.g. a tenant can move, but stay with the same support provider, or change the support provider without having to leave their home. Integrated working between LD nurses and care providers has improved service too. (ii) Bradford's First Contact was a multi-agency, early intervention, locality project that used a simple questionnaire to identify needs across a wide range of services and generate "cross referrals". So, for example, the Fire and Rescue Service might be fitting a smoke alarm, and through use the questionnaire identify the need for home care or crime prevention or benefits advice.</p>
<p><b>Bristol City Council:</b> The Carers' Breaks Dementia Service in East Sussex, which originated as part of the Demonstrator Site work commissioned by the DH in 2008, has developed to deliver 167% of its target number of breaks, while preventing nursing home and hospital admissions and saving considerable funds for the state and individuals. At the same time it works proactively with the local voluntary and community sector to promote independence of people in the mild to moderate stages of dementia</p>
<p><b>British Acupuncture Council:</b> Gateway Clinic:  <a href="http://www.lambethcommunityservices.nhs.uk/our_services/primary_and_planned_care/gateway_clinic">www.lambethcommunityservices.nhs.uk/our_services/primary_and_planned_care/gateway_clinic</a></p>
<p><b>British Dental Association:</b> The Residential Oral Care Scheme (ROCS) in Sheffield is a highly regarded scheme and highlights where innovative commissioning and integration of</p>

<p>services works well for clinicians and patients alike. It involves collaboration between family dental practices, supported by a senior dentist in the salaried service. It delivers a comprehensive training, screening and treatment programme to residential homes for the older adults in the city. It has increased access for patients, helping to avoid crises requiring emergency care and improving quality of life. It has also ensured the integration of oral health into patients' overall care plans and seen carers trained to promote oral health to residents.</p>
<p><b>British Red Cross:</b> Our Nottingham Crisis Intervention Community Support Service offers an intensive support service for those referred from their GPs, and aims to stop preventable hospital admissions. In addition to preventing a revolving door of hospital admissions and social services assessments for vulnerable older people – 89% are 70 and over – the service has been estimated to deliver fivefold savings in reduced ambulance call-outs and the avoidance of hospital admission in 75% of instances. This evidence has been recognised by the QIPP programme which also validated savings achieved through a range of our different service models. More recently some of our London services have even been integrated into Trusts' HR and IT systems, to enable and streamline electronic referrals to our service from within the existing hospital systems, and to allow easier and better access to the patient information that we need.</p>
<p><b>Bury Council:</b> Our crisis response team joins up health and social care services (and staff) to provide 24/7 cover in the community to reduce admissions to hospital and residential care. Operating under single line management, this service is making best use of resources and has added to our other shared services (Reablement and Intermediate Care) which are creating a series of common pathways that smooth the customer journey between health and social care services. Based on our experience, we would challenge the viewpoint that integrated services are a panacea. We feel that such approaches work best where there is a shared objective and a commonality in the customers being treated.</p>
<p><b>Cambridgeshire Community Services:</b> Good examples link to work we deliver in reablement – reducing the risks to individuals losing independence; support for people after being in hospital, to enable their transfer into the appropriate care setting without delay; and our joint working with mental health and primary care colleagues to identify people needing health and social care and working with them to maintain their independence in their long term condition/ mental health requirements.</p>
<p><b>Cambridgeshire County Council:</b> We have four integrated services – (i) Mental Health, social care and health services sharing responsibility; Learning Disability Partnership, social care and health in integrated teams combining specialist skills as appropriate; Integrated Older People's Services; and the Older People Care Managers working with district nurses and community matrons. This allows for closer collaboration around the individual. In the Integrated Occupational Therapy services, professional social care and health assistants are combined and prescribe equipment to meet needs. Supporting these arrangements are joint lead arrangements for commissioning.</p>
<p><b>Carers UK:</b> There are many good examples where services have been integrated on a local or project level basis, but this working does not seem to be transferable or sustained. For example: (i) Birmingham Council recently commissioned an integrated care service with a mixture of telecare, telehealthcare and homecare services that fit around people's lives. (ii) Brent integrated a series of preventative services commissioning social care outside of the public sector which resulted in significant savings to the health sector - which social care did not see the benefit of.</p>
<p><b>Chartered Institute of Housing:</b> In Blackpool, joint meeting at all levels in the partner organisations, joint training sessions and shared referral processes have</p>

<p>developed. Blackpool was an early case study of integrated working across the sectors. Public services in Blackpool had developed integrated networks at chief officer, strategic and operational levels that resulted in cross professional training, and the development of a shared referral process.</p>
<p><b>CIRCLE:</b> (i) 'Action for Carers in Employment', run by Carers UK, with 150 providers including all types of organisations, such as Age UK, the Samaritans, as well as small organisations, to use volunteers and to support carers. (ii) In the Sunderland [breaks] Demonstrator Site the partnership in the DS was the City Council (not just social services) e.g. transport and city care trust were also involved, as well as the carer's centre and carers themselves, who shaped the direction of the project. (iii) Devon Demonstrator [health and well-being checks] Site used a range of people in delivering health checks. (iv) Hastings and Rother [Better NHS Support] Demonstrator Site: 'support for carers' staff became part of the wards' multidisciplinary teams, a level of integration which was key to the success of the programme.</p>
<p><b>College of Optometrists:</b> Our Local Optical Committee Support Unit (LOCSU) has developed the Community Optical Pathway for an Adult Low Vision Enhanced Service precisely for this purpose which aims to signpost patients with low vision to local care services that are appropriate for their needs. <a href="http://www.locsu.co.uk/enhanced-services-pathways/low-vision/">http://www.locsu.co.uk/enhanced-services-pathways/low-vision/</a> A further pathway for People with Learning Disabilities is in development including with social care colleagues.</p>
<p><b>Care Quality Commission:</b> CQC addresses integration through: (i) On-going compliance monitoring function; (ii) thematic reviews, where we have highlighted on how providers integrate in order to achieve better outcomes, e.g. reviews into stroke services, how healthcare needs are met within care homes, and end-of-life care.</p>
<p><b>Devon County Council:</b> In Devon (i) Social care reablement is reducing reliance on long-term care and support hospital discharge. (ii) Rapid response services are helping to avoid hospital admissions and stabilise situations. (iii) Additional investment in equipment and assistive technology. (iv) Establishment of support groups for people with dementia and dementia cafes. (v) Integrated health and social care teams as an outcome of Transforming Community Services. (vi) Examining pathways to ensure services respond to the individual rather than making them fit the services - e.g. Day Opportunities review. (vii) Integrating the previous Supporting People funding.</p>
<p><b>Disability Cornwall:</b> We are working to create a Personalised Care Planning System, held by the individual on paper and in virtual format (if possible), understood by any statutory sector agencies that may need to access it, reviewed on an on-going basis, and including plans to increase individual capital resources as widely as possible (e.g. social capital, cultural capital, and economic capital). An increase in individual levels of capital resources can increase individual feelings of agency, choice and control, and thereby reduce the need for statutory sector, acute and chronic, intervention. NB: user-led organisations operate on very small amounts of money, relatively speaking, and every pound is accounted for. This 'extra' work needs to be funded from another source to ensure it is conducted effectively.</p>
<p><b>Doncaster Borough Council:</b> (i) In Doncaster's 'One Team Working' pilot, social workers, district nurses and community matrons work together in the same building. It makes it easier to get hold of relevant people to inform them about concerns about individuals whether social care or medical which can lead to early intervention and preventing crisis situations. It also builds support networks. (ii) Doncaster's Intermediate Care Team is fully integrated through a single point of contact; STEP's (Short Term Reablement Programme)</p>

<p>team and CICT (Crisis Intervention Care Team) provide support for up to 6 weeks to support people to recover their independence following discharge from hospital or a serious illness. This leads to better outcomes for service users as allowing people to stay in their own home leads to a speedier and more complete recovery. (iii) Joint assessment and care management: we now have an integrated discharge team. (iv) Our Rapid Assessment Project Team, a multi agency team, has been set up at the local hospital and assesses the needs of people admitted to A&amp;E.</p>
<p><b>Equality 2025 meeting:</b> The Right to Control Trailblazer shows how integration can work across different funding streams (but should be extended to cover welfare benefits for basic income and health care).</p>
<p><b>Fusion:</b> Tavistock Care and Repair should be retained and offered all over region.</p>
<p><b>Gentoo Group:</b> We are looking to develop a Connected Care Model, a more focused and integrated care and support model to help ensure an effective care pathway, tackle health inequalities and provide better care for older people to help them live independently within their own home.</p>
<p><b>Halton Borough Council:</b> A local example of a person-centred service that met the needs of the individual in a timely and integrated way is the Halton Intermediate Care Service. This offers an integrated service aimed at reducing hospital, residential and nursing admissions, as well as improving the access to rehabilitative services.</p>
<p><b>Hampshire County Council:</b> We have been successful in achieving an integrated, multi-agency approach to safeguarding, which involves regulatory services, Hampshire Fire and Rescue Service, Hampshire Constabulary, Health, and District Councils.</p>
<p><b>Hartlepool Borough Council:</b> The Waverley Allotment project brings together health, social care, employment and education services, the voluntary sector and the criminal justice system. We have strengthened our reablement services in partnership with the NHS, developed a range of extra care provision, and we work with residential care providers to promote personalisation within care homes.</p>
<p><b>Housing 21:</b> The 'Portable Care Packages' project in Bristol involves Housing 21's care workers working alongside hospital staff to continue their clients' care while they are in hospital. It is funded by a £120,000 grant from DH and developed with support by local NHS services and trusts, and by Bristol CC. Its services help improve people's experience while in hospital and when they are discharged. Housing 21's care staff provide an advocacy service for hospitalised residents, as well as acting as an information resource for hospital staff. This is particularly important if patients don't have family members able to visit regularly.</p>
<p><b>Hull LINK:</b> (i) Clear pathways (cf. stroke care, epilepsy specialist nurses, diabetes care, long term conditions service in East Hull). (ii) Services which have introduced modern systems to allow greater flexibility (e.g. GPs using online booking and extended opening times; pharmacist services for ordering, collecting and delivering prescriptions; being able to self refer to services such as physiotherapy.)</p>
<p><b>Independent Living Fund:</b> The ILF experience is that it is possible for two funding streams, where taxpayers money is assigned through different Government departments to two different programmes for legitimately different reasons, to be delivered through partnership working to achieve more than the sum of the separate parts and a coherent</p>

<p>service to the recipient. The Individual Budget pilots and more recently the Right to Control Trailblazers are identifying ways of doing this even more effectively.</p>
<p><b>Individual:</b> The Challenging Behaviour Psychology Service in Hertfordshire provides clinical psychology support to families in Hertfordshire who have a child or young person with severe learning difficulties and/or autism and who displays challenging behaviour.</p>
<p><b>Individual:</b> Torbay Council operates an exemplary unified health/social care system</p>
<p><b>Involve Yorkshire and Humber:</b> (i) Hospital Discharge is an example of where the voluntary sector can play a significant role in helping to integrate services. For example, Neighbourhood Network Schemes (such as those in Leeds) provide a range of services and activities for older people across Leeds. As well as supporting people stay in their homes they provide holistic support for people on discharge from hospital, thus reducing re admission rates. These are managed by local people who decide what they want from their scheme. (ii) Local databases of non-NHS services available are a good model for sharing information between and about services. For example, there is a council- and PCT-funded database in Calderdale (using aHub model) and the Rotherham E Market place.</p>
<p><b>Knowsley Metropolitan Borough Council:</b> Day services and supported living are examples where the user of the service knows what they want and the service can provide it by being constantly responsive. Knowsley's Centre for Independent Living is a good practice example. The centre is a one stop shop for health and disability issues, bringing together a range of related services under one roof to help people with disabilities or mobility issues to live more independently.</p>
<p><b>Leeds City Council and Leeds CH Trust:</b> Examples which demonstrate good include Torbay, North East Lincolnshire, Trafford and Grimsby.</p>
<p><b>Leicestershire County Council:</b> In Leicestershire an integrated pathway of care has been developed for frail elderly people.</p>
<p><b>London Borough of Barnet:</b> Examples of good-practice integrated services include Learning Disabilities and Community Equipment services, the latter showing good outcomes from the community retail model that we have taken forward together.</p>
<p><b>London Borough of Haringey:</b> We have improved services through integration, and reduced hospital admissions and delays in discharging from hospitals. Our delayed discharges stood at 4.6 per 100,000 population in 2010/11, from 13.5 in 2009/10. We have achieved this by establishing a joint team with the NHS, from January 2011, made up of occupational therapists, nurses, physiotherapists and social workers. This includes daily teleconferencing with our health partners, a new stroke care pathway and more prevention services.</p>
<p><b>London Councils:</b> The North West London Integrated Care Pilot brings together staff from health, social care and the third sector to improve co-ordination, with clinical leadership provided by GPs and hospital doctors. It covers a population of around 375,000 people across five London Boroughs.</p>
<p><b>Mears Group PLC:</b> We are pleased to see areas such as Gloucestershire and Blackburn where there is joint working between health and social care.</p>
<p><b>Mental Health Foundation:</b> As an example of thinking about the whole-person approach</p>



to integrated services, the Foundation's Feeding Minds report (2006) lays out the evidence linking trends in food consumption with mental ill-health, and supports the case for an integrated approach to the treatment of mental health problems, identifying nutrition as a key component; and another Foundation report from the same year on young homeless people with mental health problems pointed out that many were not getting adequate support because services rarely work together to provide the necessary help.

**Middlesbrough Council:** A good example of an integrated service that supports and enables outcomes is the Integrated Occupational Therapy Service which covers the Middlesbrough and Redcar & Cleveland Borough Council areas.

**Midland Heart:** CLG produced a document 'Guidance to Local Areas in England on Pooling and Aligning Budgets' in March 2010, to look at new ways of working to reduce costs and increase efficiency. The CLG document cites examples: (i) Putting the Front Line First: Smarter Government (December 2009) highlighted the finding from Birmingham's Total Place Pilot that for every pound spent on early year's work they could save four pounds on the costs of anti-social behaviour and severe health problems. (ii) Drug Treatment Outcomes Research Study (DTORS 2009) reports that for every £1 spent on drug treatment an estimated £2.50 was saved once reduced offending behaviour is included. (iii) Kensington and Chelsea Multi agency data sharing (iv) Newham Regenerating the Social Care Market - The Market Management Strategy takes account of the profile of the community. Newham's health economy includes a primary care trust, an acute trust and a mental health trust, who all work in partnership to implement the strategy. (v) Ealing - an early intervention panel - to promote good outcomes and cost effective services for children, the panel is multi-agency and includes representatives from Social Services, Education and Health. Panel members are able to allocate support services immediately to children and families in crisis. This ability to respond quickly is contributing to well-managed reductions in the number of children coming into care. (vi) Swindon Council's Children's Services - Integrated care and pooled budgets helped the council improve children's social care services. Services were felt to be fragmented. But by pooling budgets - to the extent that it has been announced as one of the pilots for the much vaunted community budgets - it has transformed performance. (vii) In Scotland - the Christie Commission on the Future Delivery of Public Services emphasises prevention, estimating that around 40% of public service spending in Scotland goes on tackling social problems which could have been prevented. They identified the need for a collaborative approach to improve services and reduce financial pressures and the consideration of pooling health and social care budgets.

**MS Society:** 'ENable' is a community neurological rehabilitation and enablement team set up jointly by Ealing Primary Care Trust and LB Ealing Social Services, and is an example of good practice on integration.

**National End of Life Care Programme:** The NEoLCP has a bank of good practice case studies on its website.

**NHS Blackburn with Darwen:** In Blackburn with Darwen we have achieved a joint approach through our Care Trust Plus arrangements, enabling the development of robust service specifications which drive deeper integration through joint planning and performance management. We are now working closely with the Blackburn with Darwen Clinical Commissioning Group (CCG) to ensure that the benefits of local joint working continue and develop further.

**North Tyneside Council:** Experience in Community Mental Health Team (CMHT) is positive, with staff across the health and social care community undertaking similar jobs,

and having access to the same budgets.
<b>North Teesside LINK:</b> The reablement service in North Tyneside is an excellent example of a successful, integrated service. It is hoped that this service will be expanded locally to all, over 18 years of age, and that through this integration savings will be made.
<b>Oldham Council:</b> In Oldham, the diverse range of communities demonstrate good examples of how elderly parents and relatives are looked after by their family rather than going into care. This all helps towards better outcomes for service users.
<b>Papworth Trust:</b> An excellent example is where the County Durham Primary Care Trust provided Durham County Council with £1m between 2009-2011 to grit their roads in order to prevent slips, falls and collisions which in turn would lead to hospital admissions over winter.
<b>Partners for Inclusion:</b> In Sheffield, work is being developed around integrated service provision for people with long-term conditions.
<b>Prison Reform Trust:</b> Good quality pieces of work have been undertaken on social care in prison but this has not been rolled out and remains sporadic.
<b>Regional Voices - NHS Future Forum and Social Care Engagement:</b> Torbay a very effective model - bringing social services, housing and healthcare together into one budget and with one accounting officer
<b>RNIB:</b> Newham Council and Action for Blind People initiated a wide-ranging contract to deliver a one-year pilot, mainly with the aim of increasing support for local blind and partially sighted people. 27 people got personal budgets, much higher than usual for people with sight loss. Newham focused on an "invest now - save in the future" argument, agreeing personal budgets would help blind and partially sighted people to define their aspirations and maintain their independence. We would like to see other councils take a similarly bold and innovative approach to testing out new models of service provision for blind and partially sighted people.
<b>Rotherham Metropolitan Borough Council:</b> (i) Intermediate Care in Rotherham is a good example of where services are provided in an integrated way to support people's choice and independence. (ii) Our joint health and social care service for people with a learning disability means that funding is pooled and staff are co-located <i>and</i> jointly managed. Joint point of access where all contacts into the service can be filtered and directed to the appropriate source - thus avoiding unnecessary passing of people between health and social care professions. The joint service is also responsible for an integrated response to safeguarding matters.
<b>Royal College of General Practitioners:</b> The College has showcased models of mixed generalist and specialist teams working across the primary and secondary care divide: <i>Teams without walls: The value of medical innovation and leadership</i> . Report of a Working Party of the Royal College of Physicians, the Royal College of General Practitioners and the Royal College of Paediatrics and Child Health: London, 2008., a joint RCP, Royal College of General Practitioners and Royal College of Paediatrics and Child Health publication
<b>Royal College of Nursing:</b> The RCN has identified a number of different nurse-led and innovative working practices and processes, which facilitate the delivery of integrated care

<p>for every individual accessing the care system including: single entry points, single assessments and the multidisciplinary team (MDT) , early intervention and regular needs reassessment, being adaptable and discharge planning.</p>
<p><b>Royal College of Physicians:</b> Innovative approaches, such as the shared budgeting approach being explored in Torbay should be encouraged, evaluated and disseminated.</p>
<p><b>Sheffield City Council:</b> We have many local examples of integration resulting in better outcomes in all adult social care groups (as do other areas), and we would be pleased for further opportunities to share good practice.</p>
<p><b>South East Network of Disabled People's Organisations:</b> We support the principles behind Right to Control, currently being 'trailblazed' in two boroughs in south east England.</p>
<p><b>Southend-on-Sea Borough Council:</b> In Southend the use of tools such as Health and Care Trak that assist the creation of integrated and costed care pathways across Health and Social Care, whilst at the early stage of development, are demonstrating considerable potential.</p>
<p><b>Southend-on-Sea Borough Council:</b> The overall vision for integrated locality working in south west Essex is to have health and social care staff working together in teams including social workers, occupational therapists, CPNs and practice nurses based around the two clinical consortia groups working to common systems, processes and outcomes within a single governance and management structure. This is planned in three stages culminating in integrated management structures and pooled budgets. Already in Southend: (i) S75 Agreements for the delivery of joint equipment services and for some intermediate care services. (ii) Multi-disciplinary teams for learning disability services and for adult mental health. (iii) A Single Point of Referral (SPOR) has now been implemented to ensure smooth discharge of older people from hospital and appropriate support services in place, including reablement. The second stage of this project will be an integrated rehabilitation service to support avoidance of hospital admission.</p>
<p><b>St Michael's Hospice (North Hampshire):</b> Basingstoke End of Life Fast Track Service is an example of an integrated service working well for patients in the last 6-8 weeks of life.</p>
<p><b>Staffordshire County Council</b> (i) Our Joint Commissioning Unit (JCU), funded from a pooled budget set up under Section 75 of the NHS Act 2006, reports to a Joint Commissioning Executive (former PCTs and the County Council). (ii) We also have Section 75 agreements in place with the two Mental Health Trusts in Staffordshire (North Staffordshire Combined Healthcare and South Staffordshire and Shropshire NHS Foundation Trust), with whom we deliver integrated patient-centred mental health services. (iii) The local development of Integrated Community Intermediate Care Teams has been a positive model, including the development of generic Integrated Support Worker roles and education pathways - all driven by the agenda to hasten discharge from secondary care. (iv) We are transferring £150 million of services to the Staffordshire &amp; Stoke on Trent NHS Partnership Trust. (v) The 'Living Independently in Staffordshire' service, supporting adults recovering from illness or injury, brings together social care and health professionals in an integrated, person-centred approach and makes it easier for them to work together to create a service tailored for the individual. (vi) We have led a pilot project in Staffordshire with the aim of establishing Personal Health Budgets across the 2 PCTs and the Local Authority.</p>
<p><b>Surrey Care Association:</b> In Surrey the Alzheimer's Society has employed 19 'dementia</p>

<p>navigators' across the county to help users navigate the services available and we suggest that this model could be considered in addition to the single access point for navigating other services.</p>
<p><b>Surrey County Council:</b> Surrey CC has worked hard to establish good practice-based integration of services between health and adult social care, specifically: (i) End of Life Care is run by health and administered by the Council. (ii) Dementia Partnership Board. (iii) Acute Liaison Nurses support people to be discharged from hospital sooner. (iv) Multi-agency hubs at Royal Surrey Hospital will act as a single point of access into Health and Social Care System. (v) Epsom hospital team model was recognised round the table as an effective way of 'picking people up' at the start of their admission, to fully understand their situation and what support would suit them best.</p>
<p><b>United Kingdom Home Care Association:</b> The most cited example of successful integration of health and adult social care services is Torbay, which has achieved reduced use of hospital beds, low rates of emergency admissions for those aged over 65 and minimal delayed transfers of care from hospital. Use of residential and nursing homes has fallen, with a corresponding increase in the use of homecare services. However, in Torbay, there had been an urgent need to improve the council's performance and the PCT was aware that more effective health care relied on improved social care; they were both receptive to change.</p>
<p><b>VoiceAbility:</b> There are some examples where local authorities and primary care trusts have developed close working relationships such across a number of London Boroughs.</p>
<p><b>Voluntary Sector North West:</b> (i) 'Team Around the Child' is a good example of a multi-agency approach and using serious case reviews as a learning tool. To do this there needs to be a better understanding of each other's role better ways of sharing information and data. Mapping of service provision is an essential part of this in order to improve the choice for service users. (ii) The one stop directory in 'Wirral Well': statutory partners, VCF sector and services providers/commissioners can be joined up in this process. (iii) 'Start in Salford' is a charity with users at all decision-making levels, along with volunteer tutors (<a href="http://www.startinsalford.org.uk/Salford">http://www.startinsalford.org.uk/Salford</a>): the Government could look at the use of such charities as a means of keeping down budgets.</p>
<p><b>VONNE (Voluntary Organisation's Network North East):</b> The North Tyneside reablement service was highlighted as a good example that made significant improvements to people's lives and reduced reliance on NHS services.</p>
<p><b>West Berkshire District Council:</b> There are currently good examples of integrated services at walk-in health centres.</p>
<p><b>Wirral's Older People's Parliament:</b> There is evidence from some pilot work in Wirral that close integrated working can reduce hospital admissions.</p>

## Where services should be better integrated

The need for better integration between health and social care services was taken as a given by almost all respondents – for service users to have their health, social care and housing support needs dealt with in totality, with any remaining divisions being dealt with ‘in the back room’.

*The distinction between health and social care needs is arbitrary and enforced, and it is therefore difficult to know where health and social care start and end. It is therefore crucial to the individual in need of care that these two systems can work together effectively.*

Royal College of Nursing

Four specific themes are identified below but, in addition, particular conditions were raised as encountering serious problems arising from lack of co-ordination, not least by groups set up to look after those interests – cancer, ME, Parkinson’s, end of life, and others. Hampshire County Council reported an increasing number of cases of institutional abuse/neglect which require health and social care staff to work together so that quality issues can be picked up at an earlier stage.

A number of respondents identified the need for a more streamlined, person-centred, multi-disciplinary process for assessment and identification of needs. Reablement and intermediate care services needed to be better integrated. And integration was seen by some to be particularly important in relation to care for older people and people with long-term conditions, not least because this has significant potential to produce further savings for both health and social care budgets. For example, if people with complex conditions, which straddle traditional categories, were not looked at ‘in the round’, they could lose out on the services that may make all the difference to them, for example because vision and hearing difficulties are not picked up.

### Transition points

Key transition points were identified by a number of respondents as being particularly important, such as when moving out of residential care into supported living, moving onto continuing health care, or being discharged from health to social care. Point of entry to care services can be highly significant because whoever undertakes the initial signposting to services will have significant implications for the resulting outcome. At the other end of the process, the hospital discharge process is often rushed. More

'joined-up' discharge planning would help to ensure that people are not sent home (often late in the evening or at the weekend) without support; that domiciliary care agencies have the information, including about medication, that they need; and that necessary equipment is available.

Several respondents argued that there is a need for greater integration and shared resources between agencies to ensure people have access to transport to services and to social facilities – part of a wider issue of the relevance of other public services to which we return below. There was seen to be a particular issue for older people who, as a result of a lack of co-ordination, are often in hospital much longer than is necessary. Follow-up calls were suggested for a few weeks after discharge to see what support gaps have arisen, and make sure that no one has fallen through a gap.

*We are experiencing an increase in delayed discharges from our hospices following respite care as their social services care packages at home are being cancelled. Lack of integration at this key transition point leads to escalating, avoidable health costs as well as individuals feeling unsupported and concerned that the right package of care won't be in place when they leave.*

Sue Ryder

*Particular attention needs to be paid during periods of transition. For example, when young people are moving into adulthood, health, education, employment and social care need to work together to ensure young people achieve their full potential.*

National Development Team for Inclusion

*Weeks after a hospital discharge, care packages are not correct or not working, OTs have not provided essential equipment, GPs and DNs are not informed or involved, medication is not correct etc. etc. All of this results in further hospital admissions.*

Individual

### **It's not just about health and social care**

Most submissions focused on health and social care services: within those organisations as well as between them. For example, the roles and responsibilities of the organisations being set up as a result of NHS reorganisation were identified as in

need of resolution. But many submissions argued that, in order to achieve both better outcomes and value for money, integration should be viewed across *all* public services in order to meet the wider public health agenda. In two-tier areas, this should encompass other county council functions such as transport and second-tier activities such as housing, leisure and environmental health.

Housing was identified by all the housing-related respondents, and by many other agencies, as needing to be better integrated. A lack of housing can impede access to treatment, recovery and social inclusion. At present, however, housing benefit departments, council accommodation, warden controlled facilities, housing adaptations, disabled facilities grants etc. can sit outside the system. In particular, specialist housing such as extra care housing and sheltered housing itself play a role in integrating a range of community and health services. A housing representative would therefore be of value on health and wellbeing boards.

DWP was also identified for its role in integrating recovery and rehabilitation to work. One respondent, an individual, said: *'If we all enjoyed good relations with the DWP, and felt they were looking out for us, rather than looking to pick holes in our benefit entitlements, it would empower disabled people and help us to achieve our goals rather than holding us back in fear and frustration.'* The Independent Living Fund (ILF) commented that multiple funding streams, each with its own set of rules and criteria, are often brought together to form a complex and sometimes overly burdensome care package. For example 7.5% of ILF users also receive funding from Supporting People and 11.6% receive NHS funding. Others receive Disabled Facilities Grants and Access to Work funding; in addition to the funding they receive from the ILF and Adult Social Care (ASC).

Joining up with Job Centre Plus and employment support streams were specifically identified on the basis that health and social care support can restrict disabled people's ability to enter employment. Integrating with support streams such as Access to Work and social care support could get round gaps that currently hold people back as is being promoted in Trailblazer areas.

The importance of integrating the voluntary sector for some activities such as training was also identified.

*The policy direction set by the Department for Communities and Local Government to move towards a more local, place-based approach to public services is to be welcomed, and a wider*

*expansion of community budgets would facilitate this integration.*

Hampshire County Council

*By design, services could be better integrated around the individual if at the outset there was inclusion and understanding of how a range of different services must come together to meet an individual's needs. This requires commissioners to have an understanding not only just of health but of others including social care, housing, employment and financial support services.*

Turning Point

*The Government's emphasis on localism and the Big Society allows local areas to determine the best way to organise public services. Care closer to home should include a wide range of approaches involving more than just the integration of NHS and social care services but including housing, transport, education, employment, leisure and welfare services.*

NHS Confederation

## **Information and communications**

Many respondents argued that technology could facilitate information provision for service users and carers, as well as social workers and NHS staff. A number of suggestions were made: GP surgeries could act as a hub of information and advice; better signposting and service directories could be based on an integrated database; it could be the responsibility of an independent body (a user-led local Centre for Independent Living was mooted). Improved communication between hospitals, GPs, pharmacies, residential settings, carers, home support and clients, was necessary to avoid the resulting costs, confusion and anxiety.

*'Silo working' across health and social needs to be avoided.*

*Whoever first comes into contact with the individual needs to take responsibility for ensuring that they are signposted effectively. 'Tell it once' should be promoted across health and social care.*

Stockton Council



## Equalities issues

Equality of opportunity was, it was argued, denied to some groups, not only because of their condition, but because of their community. A more positive communication/engagement model was necessary to identify the most vulnerable people, out of the mainstream or hard to reach. These points were made in relation to sexual orientation and to ethnic origin, for example. Inequality of access to effective mental health services was raised because of the non-integration of “working age adult” and “older adults” mental health services. And the prison population was identified as being excluded from existing systems: the Prison Reform Trust suggested that local authorities should assume responsibility for this. Prisons contain significant numbers of people with long term conditions, including older people and people with a learning disability. Care pathways, the Trust suggested, need to include prison and recognise the needs for long-term low-level care.

*For some ethnic minority communities, diabetic patients get visited by a nurse for injection at 8am, and need to have care immediately after, food for example, but the care worker doesn't arrive until 10am. This leads to time being wasted for the health worker. Health and Well Being Boards should make this an area for assessing how client-focused service provision is in a particular locality.*

BECON (Black Minority Ethnic Community Organisations Network)

## Achieving better health, care and value for money

### Better user outcomes

As discussed earlier, most respondents judged that integration at the very least means looking holistically at each individual's needs, focusing on the patient and outcomes, not components of care.

*Integrated services have the potential to stop the revolving door associated with many customers. Joint-working protocols with teams across health and social care such as mental health, housing, hospital discharge, drug and alcohol teams, housing and children's services could achieve this.*

Bury Council

Although this was a specific part of the engagement, respondents tended not to address this specifically under this heading, having expressed their views elsewhere. It was almost regarded as tautological:

*Where possible money saving and efficiencies will be an inevitable by-product of better integrated services.*

Involve, Yorkshire and Humber

By reducing duplication through integration, ensuring engagement from stakeholders and sharing priorities, it was argued that outcomes will be improved for service users and communities. Respondents mentioned service users benefiting through specifics like avoiding blocked beds, preventing unnecessary admissions to hospital, reducing use of anti-psychotic medication, and ensuring that preventative work was carried out so that minor issues did not become major ones. This was seen to save the NHS money further down the care pathway.

*Careful multi-disciplinary working is vital to ensure individuals get the right support as they move from one system to another; this will help to prevent crisis and achieve successful enablement of service users.*

Autism West Midlands

The roles of health and wellbeing boards, and of information and communication, were explicitly mentioned by a number of respondents. Respondents generally were very positive about the potential of health and wellbeing boards. By enabling closer

involvement of relevant local authority departments such as housing, environmental health, planning, and leisure services, they would be able to undertake a strategic role in promoting collaborative behaviour as well helping local partners recognise their mutual dependency.

The London Voluntary Service Council considered that integration would need to be promoted by inclusion of local voluntary and community sector representatives on the boards, *'as it is to the voluntary and community sector to which users turn when their needs are not addressed by statutory services.'*

*[Voluntary sector] representation on the health and wellbeing board is crucial to continue the engagement already begun through the existing structures and city frameworks. This will also offer the sector opportunities to advocate and challenge, provide influence, partnership development and the allocation of resources can be better informed.*

BASIS (British Autism Study of Infant Siblings) Network

It also noted that the boards would require more powers and measures to ensure that clinical commissioning groups take account of their recommendations, while the London Borough of Barking noted that *'they will need to be backed by adequate funding, not shared poverty'*.

Better integrated information and communications must by definition, it was argued, assist better outcomes – preferably from a single source and incorporating for example telecare and telehealth. Major benefits could arise for the back office. But better communications, especially using modern technology, could also enable frontline staff to communicate directly across organisational boundaries and more quickly in response to a home visit or other client contact. Some submissions considered that there must be an element of compulsion for care organisations to share data properly and a way found through legislative barriers:

*Do not allow 'data protection' to be used as an excuse for failure to integrate.*

Bradford Strategic Partnerships

The National Institute for Health and Clinical Excellence (NICE) also noted that its new responsibility of providing quality standards on adult and children's social care, and their influence for improving performance in the NHS, social care, and public health,

will encourage the necessary connections along care pathways between clinical care and social care, together with links with public health. This will increase the potential for achieving outcomes shared by the three sectors as well as each sector's own priority outcomes.

*Quality Standards will underpin the commissioning process and give focus to the improvements in service quality necessary for the NHS outcomes framework.*

National Institute for Health and Clinical Excellence (NICE)

*Evidence for this is often qualitative or anecdotal in light of the costs involved in robustly evaluating programmes. However, where evaluations of integration case studies do exist, they show a range of benefits, including: reduction in length of stays in hospital; reduction in readmissions; lower use of hospital bed days; reduced and close to zero delayed transfers; higher level of patient confidence in NHS; improved patient satisfaction.*

The Royal College of Nursing

### **Cost-effectiveness**

The same issues which benefitted user outcomes should also improve cost-effectiveness. The Local Government Association's Adult Social Care Roundtable (local authority chief executives, directors of adult social services, and leading members) found widespread agreement that resources needed to shift out of acute settings and into community-based services, including adult social care; most participants felt that even a small diversion of the acute budget could fund significant improvements to capacity and quality in social care. Integration implied some tough communications challenges:

*Leaders at all levels need to educate the public that hospitals were not [always] the right answer, and that closing hospitals could allow resources to be used much more effectively.*

Local Government Association Adult Social Care roundtable

In summary, the reduction of duplication and waste currently in the system, and the more effective and efficient utilisation of resources available, ensuring people receive 'the right care, in the right place, at the right time', pooling resources, improving the use of technology across boundaries, reducing bureaucracy, reducing unnecessary

processes and time spent on managing separate systems, should all, it was argued, result in more innovative and cost effective solutions.

*Work on reablement demonstrates a 33% reduction in cost of care and better user outcomes. Every £1 invested in social care saves NHS £1.30.*

North Yorkshire County Council

*The Care Quality Commission has suggested that better health and social care integration could save the care systems £2 billion.*

The Royal College of Nursing

*Good integration reduces the number of professionals visiting/working with a client; fewer journeys; reduces hospitalisations; prolongs independence. Everyone wins!*

Wirral Older People's Parliament

However it was noted that integration is not enough on its own:

*Integration on its own may not achieve this. Services should be designed and delivered in line with best practice and best value principles, learning from others and retaining the customer at the centre, using lean principles.*

Rotherham Metropolitan Borough Council

## Barriers to integration

Respondents identified a wide range of barriers to integration: structural, cultural and financial. Underpinning these barriers was a sense of the value and potential of integration just not yet being fully appreciated, not only between the health and social care services but across all the many statutory and non-statutory agencies which impact on outcomes. This is not surprising, for policy, pathways and the professions themselves have traditionally been developed in 'silos'. The benefits of integration therefore needed to be stressed at all levels, which perhaps might be one by-product of this engagement.

*We hope that one output of this consultation will be to promote the benefits of integration with eye care services to our colleagues in local Government, communities and social enterprises.*

College of Optometrists

### (a) Structural barriers

(i) *Separate budgets*: Several respondents commented that agencies can be reluctant to invest across boundaries. There are in any case rules which impede pooling budgets at present, with degrees of ring-fencing, which partly reflect the source of those funds – Government or otherwise. This was seen to reduce the flexibility implicit in integration. Further, budget formulation and accountabilities are separate, without the ability to account financially for savings or added expenditure arising for one organisation as a result of the actions in another organisation.

*Incentives within the current health system, including those linked to the NHS tariff, current ring fencing around health funds and rules around financial accountability, pose a barrier to the integration of health and social care services.*

Society of Local Authority Chief Executives.

(ii) *Data systems*: Both the NHS and local Government are made up of complex organisations, each with responsibilities for different aspects of commissioning and service provision and, as respondents pointed out, each working within different IT operating systems, different management frameworks and different staffing structures. Sharing of IT systems and information, system infrastructure, and data requirements was seen to be a significant barrier. Although it can be achieved within the existing

legislation, it was evident from submissions that there is not always a willingness to share information across organisations, nor the development of systems and processes to enable data to be shared, for example GPs getting permission to share data with other professionals.

*IT integration can be impeded by the complex legislation surrounding data sharing which the Government would need to take a lead in resolving.*

Surrey County Council

(iii) *Lack of common standards*: It was argued that separate health and social care indicators, standards and strategies do not encourage an integrated approach. This may in part be ameliorated once NICE fully assimilates its new responsibility of providing quality standards on adult and children's social care.

*If we are to truly integrate then there has to be consistent minimum standards across the social care and health departments.*

The Glenmore Trust

(iv) *NHS reorganisation*: There was some concern about how helpful NHS reorganisation would be to the process of integration. The changes underway within the NHS are not yet finalised which, it was argued, could generate some tension between local and regional devolving of power and budgets within the NHS so that until current structural changes are complete, formal integration of services could not take place at a local level. NHS commissioners increasingly work on cluster wide issues with a loss of focus on local authority areas, which makes better integration more difficult to achieve.

*NHS reorganisation, and the dissolution of strategic health authorities and primary care trusts before new leadership and organisational arrangements are in place, offers a fragile framework in which to construct strong new partnerships.*

Barnsley Council

**(b) Cultural barriers**

(i) *Models of care*: A barrier may be created, in the view of a number of submissions from local authorities and social care agencies, by what might happen to the social model of care if health and social care organisations and budgets were brought together. These submissions emphasised that the focus should remain on the social model of support and not the medical model and that integration must not be achieved by the 'medicalising' of social care and housing. On the other hand, the Mental Health Foundation said that social care for people with mental health problems and people with dementia has tended to be dominated by a medical model, rather than a disability model of care; the Foundation argued that social care for people with mental health problems should not be seen as just a social/health issue, but should be recognised as a disability issue that requires a truly integrated response across a wide range of organisations. The Papworth Trust concluded that their call for health and wellbeing boards to include representatives from social housing and welfare, reported elsewhere, would help to ensure that the Boards' focus is on the social model and not medical model of disability.

*GPs don't necessarily understand learning disability/mental health need well enough to recommend the best services for them. They can be quite 'medicalised' in their outlook.*

KeyRing

(ii) *Different organisational cultures*: The most mentioned barrier to integration was the different organisational and professional cultures in various organisations, particularly in the health and social care fields but also the voluntary sector and the private sector. It was argued that cultural barriers to integration can range from varying management styles across organisations, differing values and strategic priorities and differing political environments. The tensions between disparate organisational approaches can at times stand in the way of developing a unified culture. One respondent, Involve Yorkshire and Humber, concluded that '*professions should redefine their responsibility as "wellbeing" not just health and/or social care*'. It takes time to develop trust between organisations if there are different cultures. Further, local Government has, by definition, a clear *local* agenda, with a focus on meeting the evidenced needs of the local population, while priorities within NHS organisations are driven by the *national* agenda.



*Barriers still remain between health and social care in terms of philosophy, ethos and culture.*

Nottinghamshire County Council

(iii) *Lack of willingness to work together.* A number of responses reflected on an unwillingness to work in partnership and share resources and good practices: services tend to work within their own silos. It was argued that the NHS is siloed between primary, secondary and tertiary care, and again between NHS providers and social care. Working relationships were not always effective across professional boundaries.

*Apart from some well known examples (Torbay, Cumbria, Knowsley etc.) General Practice and Social Care are too busy to integrate without incentivisation or strong leadership.*

Individual GP

(iv) *Lack of knowledge or understanding of different services:* Most concerns expressed by respondents were about health professionals' knowledge of the social care services, rather than vice versa, and opportunities to work together. Some continuity and historical knowledge may have been lost through changes in staff or in organisational changes. A theme from a number of non-statutory social care agencies was that GPs were not generally well aware of the role of social care professionals.

*GPs are often too keen simply to refer their patients into social services and they have little or no understanding of the role of the third sector (VCS and social enterprise) in providing care services. There is too great a gap between GPs' perceptions of what users want, and the actual reality.*

Future North West

### **(c) Financial barriers**

(i) *Resource constraints:* A number of local authorities spoke of lack of funding as a barrier to integration and the 'cost shunting' from health to social care, with a consequent lack of trust and positive working relationships between the key agencies. The financial pressure put on health services, and the approach taken by some PCTs, it was said, means that cost savings are usually focused on community services which effectively 'cost shunt' to adult social care budgets.

*While statutory agencies continue to be under financial pressure to deliver efficiencies and still cope with demand, there*

*is always the potential for disputes about costs that get in the way of effective integration.*

St Helens Council

(ii) *Costs of integration*: Any integration costs money in the short term. Working in an integrated way can be more challenging for staff than taking the easier route of carrying on the same way. Few if any respondents argued that it would not be worth it, but it was still acknowledged that aligning adult social care with the NHS service had a cost attached to it.

*The resources are just not there. How can innovation and developments be resourced in a contract and procurement culture when so much competition between those who once were partners exists?*

Voluntary Sector North West

(iii) *Free vs. means-tested service*: The alignment of health and social care legislation, a number of respondents commented, does not assist alignment of budgets, in that health is free at the point of delivery and social care is subject to an eligibility framework and means testing. While this distinction exists, therefore, resources have to be directed at determining what elements of a person's care are health or social care related and which statutory organisation is responsible for funding their respective element. Pooling budgets could help to go some way towards addressing the barriers that these fundamental differences present.

*The NHS is free at point of need to users; social care is means-tested - a perverse incentive for keeping older people in a free hospital bed.*

Bupa

## Who needs to do what to progress integration?

Some respondents feared that organisations might display defensiveness when confronted by the need to integrate with others.

*In the current harsh financial climate, there is a real risk that leaders will adopt a fortress mentality in which they focus on the survival of their organisations regardless of the consequences for others.*

Midland Heart

However, in the event, almost all respondents enthused about integration. There was little, if any, evidence of defensiveness in submissions. In fact the tone from all directions was: 'This is right – let's get on with it'.

*In the longer term, why not just accept we all work under the 'Health' umbrella and merge Health and Social Care totally under one organisation in each area.*

Middlesbrough Council

A number of suggestions were made for how integration can now be progressed, not least dealing with the barriers identified above. Some suggestions, outlined below, relate to the relatively short term, for example the roles of the health and wellbeing boards, dealing with some of the requests for guidance being made, and starting work on some of the information and communications issues. Others are more long-term. Progressing integration would involve all players but initially much of what has been identified by respondents would fall on the Government to prepare the way.

### **Government**

(i) *Clear strategic direction needs to be set:* Local Government and NHS respondents in particular argued that Government should set the agenda, produce a cross-departmental strategy for personalisation and integration, and set deadlines for the achievement of various levels of integration. It would also need to commit resources to taking forward the vision and strategy.

*The need for integration requires it to be championed from the top i.e. the Secretary of State and the Department of Health, and played out in their behaviours. Successive Secretaries of State have placed emphasis on the NHS rather than integration.*

*There is no need for yet more research - the need is to get on and do it.*

National Development Team for Inclusion

(ii) *Leadership would be key at all levels.* Although some argued that if change was going to work, it should be 'bottom up', the appointment of a national integration lead on the NHS Commissioning Board was suggested for developing an integration strategy to encourage and recognise success. The establishment of senior management qualifications in integrated care for people working in the public sector was also suggested.

*A national director would not dictate down but could collect, collate and share the numerous and varied examples of integrated services taking place across the country. A personalisation and integration lead on the Commissioning Board should also have responsibility for promoting a more inclusive personalisation agenda.*

Sue Ryder

(iii) *Clear roles and responsibilities* would have to be asserted by Government. This pertains not only to taking forward integration generally but also to specific issues such as safeguarding so that health and social care staff can work together to prevent and respond to cases of institutional abuse/neglect.

*The Government should do more to set out just where responsibilities for integration will lie.*

Parkinson's UK

(iv) *Funding rules need rationalisation* on a number of levels to encourage integration, it was suggested. Some respondents commented that there was a need for mechanisms to enable funding to be transferred between organisations, and contractual levers to ensure integrated outcomes are met. Many respondents argued that pooling budgets should be encouraged, along with the creation of more flexible funding streams. The Community Fund holding was suggested as having the potential to bring personalisation into communities and encouraging services to join-up and pool their local budgets around mutually agreed outcomes for a local community. At the same time, guidance from the Government would be necessary, it was suggested, on the problem caused by different rules regarding an individual's financial contribution for

health and social care (as the NHS is free at point of delivery and social care is charged for).

*The Government needs to provide guidance to the problem caused by different rules regarding an individual's financial contribution.*

Kent County Council

(v) *The need for incentives*: While many respondents considered that integration was an incentive for action in its own right, a number also suggested that the Government would have to incentivise in some way. Pooled budgets between health and social care could drive integration, as suggested above, but at present it was argued that there are no real incentives to establish them. Aligning priorities and outcome measures more closely across health and social care would also incentivise integrated working.

*Innovative services are difficult to create without goodwill, incentivisation or additional resource of some kind to develop the project.*

Bury Council

(vi) *Learning from good practice*. Respondents from all sectors were enthusiastic about the power of exemplars and learning from good practice elsewhere. It was suggested that the Department of Health take a lead in summarising the evidence and making it more widely available, demonstrating the flexibility and range of options which will allow local authorities and partners to determine the most appropriate model that suits their locality.

*Exemplar projects that deliver quality and productivity improvements should be shared across health and social care to facilitate learning and networking.*

NHS Hertfordshire

(vii) *Communications and information are key*: The Department of Health was identified by several respondents as the lead organisation in promoting integration, setting out the evidence, providing guidance relating to partnership agreements, and demonstrating the options whereby the local partners could formulate the most appropriate model.

*Ensure that communications within and between organisations/agencies are improved, including putting in place*

*systems for open communications between users and providers. Sharing will improve value for money, save time and costs.*

Physical Disabilities and Impairment Partnership

### **Local Government and Health working together**

(i) *Promote joint planning.* It was argued that clear partnership agreements would be required along with joint governance processes. One organisation, it was suggested, should act as a lead for each specialist service area.

*There needs to be much more focus on joint service plans - staff working together lower down the organisation, integrated processes, e.g. single assessment process, pooled budgets, 'One Team Working' approach.*

Suffolk County Council

(ii) *Cultural change needs local leaders*, including parties not previously involved, notably in housing. It was argued that management teams and strategic directors should take responsibility, with a shared understanding of the purpose, aims and benefits of integration. It was suggested that development team and lead officers could take forward joint service plans involving staff working together lower down the organisation. Several respondents felt that cultural change and the development of trusting relationships between organisations will enable integration to be progressed:

*Culture and behaviours at all levels needs to be addressed if we are to make any progress in terms of integration. The workforce needs to change, becoming more responsive to the social care market, and in particular needing to be more responsive treating the individual as an individual, not a condition, and with greater respect.*

East Riding of Yorkshire Council

*Integrated working is not solely about organisational mergers. It is more about cultures, behaviours and values. Establishing constructive relationships and ethos of joint working at different professional levels and across the NHS, local government and partners including the voluntary sector, communities and other*

*bodes in lower-tier of local authorities is essential to effect change.*

NHS Confederation

(iii) *Placing the user at the centre of change.* A number of respondents emphasised that this is a pre-condition of change, that all sectors should be encouraged to be involved, and that the necessary training for staff is prioritised.

*True engagement with customers and patients in service design is key to the fundamental shifts needed, and to ensure that customers understand the new service.*

Bury Council

(iv) *Progress on aligning data, record and information systems* between the NHS and local authorities was a key issue for a number of respondents for facilitating integrated working. Medical records need to be quickly accessible by hospital staff, for example. The scope for 'smart' technology for joint access of key information through safe, defined channels to reduce delays and identify problems, was raised in order to engage with key parties simultaneously. At a meeting with people with learning disabilities and autistic spectrum disorders, it was suggested that adults with learning disabilities be provided with their Health Action Plan in a portable format.

*There needs to be a lead on information sharing, without which any integration/co-production is difficult.*

Bury Council

(v) *Align policies and procedures between the services.*

*Move towards one standard set of conditions so that practitioners are not, as can be the case, working towards two different sets of organisational policies and procedures for HR, etc.*

Middlesbrough Council

(vi) *Information-provision and communications.* A number of submissions argued that local authorities should take responsibility for information services in their area, working within national guidelines on the content and extent of an information strategy. It was suggested that the health and wellbeing boards could have oversight of local information arrangements, which could include reliable information on a wider range of public, voluntary and independent sources of support than health and social care.

*Commit appropriate resources to taking forward the vision and strategy ensuring on-going and effective communication and constant patient/service user and staff engagement.*

Leeds Council and Leeds CH Trust

*Without robust information strategies at local level, we cannot envisage the development of the expert patients/citizens and carers and capable communities as envisaged by the Government.*

Standing Commission on Carers

### **Commissioners and providers**

Providers had a number of suggestions for commissioners:

(i) Commission on a more integrated basis:

*Ultimately, it will be how services are commissioned that will drive integration. If we commission for individual products such as domiciliary care or telecare,...you will by design end up with a less integrated offer. If you commission at a broader level with challenges around designing systems that enable people to stay healthy and happy at home for longer, then providers will respond with more integrated, better value solutions.*

Mears Group PLC

(ii) A potential role was noted for registered providers to play in offering their central services (for instance finance, HR, policy, learning and development) to smaller voluntary care and support providers which may be a more cost effective for them than employing their own teams/individuals.

(iii) As discussed elsewhere, a number of submissions commented on the important role which housing providers have in social care. There was a view that housing providers should be more explicit in communicating their roles.

### **Health and wellbeing boards**

The role of the health and wellbeing boards was widely welcomed as providing local leadership through the priorities identified by the Health and Wellbeing Strategy, and a number of comments were made about its membership. Clinicians, housing providers, and local non-health or social care service representatives were all suggested.



*Health and wellbeing boards must develop as the central mechanism for bringing services and stakeholders together to ensure joined-up services that reflect the findings of their local Joint Strategic Needs Assessment (JSNA) and priorities for service development.*

Hartlepool Borough Council

A fund was also suggested for the health and wellbeing boards and Clinical Commissioning Groups, to support investment in integration.

### **Voluntary sector**

There was general acknowledgement of the important role to be played by the voluntary sector in taking integration forward, not least in bridging the gap between hospital and community, acting as advocates and part of the network of support across many specialist areas.

Submissions from voluntary organisations pointed to the need for this to be better recognised generally. And this was also endorsed in a number of statutory submissions. A 'significant' way of integrating voluntary sector contributions into the care pathway was suggested in a case study put forward by Halton Borough Council:

*A discharge meeting with a stroke patient and family consisted of one social worker and four clinical staff. All of the health needs and the basic social care needs (minor adaptations) were dealt with, but there was no-one who could consider that the patient wanted to go and get his morning paper, wanted help on a computer to continue his work on the family tree and go for a pint on a Friday. These areas could be supported by the voluntary or community sector yet they are very rarely included in the pathway or any discharge process. This is an innovation that could significantly improve integrated care.*

Halton Borough Council

# **Prevention and early intervention**

## Prevention and early intervention

### Engagement questions

#### 4. What are the priorities for supporting greater prevention and early intervention?

- a. What do good outcomes look like? Where is there practice-based evidence of interventions that support/enable these outcomes?
- b. How could organisations across the NHS and Local Government, communities, social enterprises and other providers be encouraged and incentivised to work together and invest in prevention and early intervention including promoting health and wellbeing?
- c. How could we change cultures and behaviour so that investment in prevention and early intervention is mainstream practice rather than relying on intervention at the point of crisis? How could we create mechanisms that pay by results/outcomes?
- d. How could individuals, families and communities be encouraged to take more responsibility for their health and wellbeing and to take action earlier in their lives to prevent or delay illness and loss of independence? How could we promote better health and wellbeing in society?
- e. How could innovation in prevention be encouraged, identified and nurtured?

## What do good outcomes look like?

Respondents generally approached this question from two perspectives, that of the **user** and of the **service provider** (and sometimes both). The user perspective was mentioned far more often.

Starting with the user perspective, enabling people to live **independent lives** was mentioned most often, followed by **quality of life**:

*Good outcomes should focus on the quality of life for the person, enabling independent living and enhancing wider well-being.*

Housing and Ageing Alliance

A wide range of other suggestions were made, from the more general such as having needs met and user satisfaction, to more specific definitions such as well being, feeling valued and self-reliance. A number of respondents mentioned being informed about the range of services available as a sign of effective prevention. Others saw good outcomes in terms of the impact on an individual's health.

Some respondents focused on the type of life effective prevention can enable people to lead, for instance being less socially isolated, engaging with the local community or being economically active. A couple of respondents conceptualised good outcomes in terms of people being able to live the lives they choose:

*When social care needs are met from the onset and dealt with as soon as possible, people can lead the lives they choose, remain economically active for longer and, in the long-term, cost the system less in terms of health and care services.*

VoiceAbility

A number of respondents felt that outcomes should be defined by users:

*Good outcomes are those that help people gain or regain their wellbeing and maximise their quality of life as defined by them.*

Hartlepool Borough Council

*Good outcomes are outcomes agreed between support staff and individual recipients of care. While they may lead to a reduction in the need for social care (or other) support, they should also focus on quality of life - especially if the*

*support need is long-term, for example, for people with a learning disability. Evidence suggests outcomes are more likely to be achieved when service users have been involved in drawing them up as equal partners in care.*

Mental Health Foundation

Other respondents saw outcomes in process terms, mentioning early access and diagnosis.

Among respondents who looked at this issue from the service perspective, reducing involvement with social care and health services was mentioned most often, followed by reducing hospital admissions.

A number of respondents discussed the mechanics of defining outcomes. The difficulties in doing so were mentioned by a couple:

*Good outcomes are difficult to gauge in this area e.g. how can we be sure that early intervention resulted in someone not falling into "crisis" at a later stage. It is likely, often, that there is a causal relationship, but you cannot prove it.*

Middlesbrough Borough Council

A couple of respondents stressed the importance of defining good outcomes:

*Establishing a definition of prevention and early intervention is key to supporting better commissioning, evaluation and pan-professional working. However given the breadth of services which can legitimately provide preventive help we should not seek to define prevention and early intervention by creating restrictive 'lists' that stifle the potential for innovation or personalised interventions.*

Age UK

*A shared understanding of the definition of prevention and early intervention needs to be owned and shared with all agencies to promote clearer understanding.*

Bracknell Forest Council

## Practice-based evidence of prevention

A wide number of examples of practise-based evidence and examples of prevention were raised in the engagement:

<p><b>360 Foundation:</b> Life style matters programmes (NICE 16) is a project that can have huge impact on the quality of lives for frail older people at risk in the community.</p>
<p><b>Association of Chief Executives of Voluntary Organisations (ACEVO) roundtable:</b> Living Well community options initiative - easy options team which is multi-agency, which brings usual range of tensions but also possible benefits / ESRC / JRF 4 year research project on homelessness and complex needs just published - identifying points at which services could have intervened preventatively.</p>
<p><b>Age UK:</b> Age UK has a great deal of practice based evidence on the effect of preventative services. Age UK has published <i>Prevention in Practice</i> which gives many examples of preventative services focusing on information and advice, practical support <a href="http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Healthandwellbeing/61_0409_prevention_in_practice_service_models_methods_and_impact_2009_pro.pdf?dtrk=true">www.ageuk.org.uk/Documents/EN-GB/For-professionals/Healthandwellbeing/61_0409_prevention_in_practice_service_models_methods_and_impact_2009_pro.pdf?dtrk=true</a>). SCIE have also published practice-based evidence in their recent publication <i>Preventing loneliness and social isolation: interventions and outcomes</i> (research briefing 39, Oct 2011)</p>
<p><b>Agewell consultation event:</b> There seemed to be a high level of awareness of health preventative initiatives particularly lifestyle services such as Sandwell Stride Health Walks, Bike Rides, Active Sandwell, Extend, Falls Prevention and Healthy Eating (Slimwell &amp; Cookwell).</p>
<p><b>Leeds City Council and Leeds CH Trust:</b> The model used in Barnsley to encourage people to consult if they had a cough for more than three weeks has led to significantly better early identification of lung cancer. The model employed was one of community champions whereby natural leaders in the community started to ask people about their cough and encouraged them to seek advice. This model could be replicated in all communities. There are very positive lessons that can be learnt from the 'Ageing Well' Initiative.</p>
<p><b>AVON and LA Conference:</b> LGBT partnership's sexual health work with men at high risk of HIV generated £5-8m savings in Manchester.</p>
<p><b>Barchester Healthcare:</b> Barchester Fitness with Care programme, the Cooking with Care programme, and musicality initiatives which encouraged the individuals we support and staff to shape up joint programs for personal and group fitness, life skills and social skills. The POPS schemes and the QUIP initiative have achieved good outcomes in a wide variety of areas and across broad partnerships because seed corn money was available and time was freed up for collaborative planning.</p>
<p><b>Birmingham Advisory Council Of Older People:</b> Modern care centres in Birmingham.</p>
<p><b>Bristol City Council:</b> The council's private sector renewal policy assists owner occupiers in remedying hazards in the home. Home Action Zones initiative aims to keep people safe and warm in their homes eg safety measures. Working with the NHS Public Health teams in relation to falls prevention and healthy lifestyle choices.</p>
<p><b>British Dental Association:</b> The proposed oral health indicator for five-year-old children in the Public Health Outcomes Framework will promote collaborative working between health and social care professionals locally, and between family members.</p>
<p><b>British Geriatrics Society:</b> There is a reasonable body of evidence supporting 'anticipatory</p>

care' for all older people (Beswick AD, Lancet 2008).

**Bromley Experts by Experience and Disabled People Against Cuts:** Trafford Council have carried out research to show that lower level interventions saves money in the longer term. The Independent Living Strategy showed how investment in independent living and meeting the support needs of disabled people saved money in the long term.

**Bury Council:** (i) Our reablement service (where there is high satisfaction rates although 46% of participants leave the service with no long term packages). (ii) Our local Dementia Café, which supports patients, customers and carers in relation to early diagnosis support, on-going information and informal user led support. This is provided in a non-traditional community setting, meeting the needs of the target group. (iii) The one front door approach, adopted here locally, is providing robust evidence as to the success of people's lower level needs being met differently through these services, therefore avoiding a further escalation of need.

**Cambridgeshire County Council:** Our Supporting People programme sets targets every year to increase the number of people who achieve independent living in short-term supported housing services. In 2010/11 73% of the people who left short-term services left with a positive outcome (69% in 2008/09). Further examples of positive outcomes for people can be seen on the DVD 'It's All About Us!' Made by service users, it features stories of people who have used the self-directed support process and a personal budget to make their own choices about how their support is organised (<http://www.cambridgeshire.gov.uk/social/selfdirectedsupport/casestudies/>).

**Chartered Institute of Housing:** The Supporting People programme led to the development of housing related services that supported prevention across a wide range of service users (see Cap Gemini's report (2008) and reports from the Audit Commission). The partnership between Wakefield District Housing (WDH) and the local PCT in getting messages to these households and supporting/ encouraging them to access the health and support they needed. Referrals can come through tenants' self referring, from other providers and partners, but is predominantly through WDH's own estate staff, debt advisors etc.

**CIRCLE:** Devon Demonstrator Site provided an example of good outcomes. There are 107 GP practices in the area who were all invited to participate, but only 35 decided to take part. Devon also worked with pharmacies and a peripatetic nurse. Also included work with young carers, and bespoke work with BME carers through Hikmat. Learning/outcomes: carers valued the approach; 91% of carers said they would recommend the health and well-being check to a friend. Carers said it enabled them to look at their caring role in a new way. The project was effective in making GPs more carer aware with a result of an increase in read coding by 75%. Camden Demonstrator Site provided an example of good outcomes: Summary of Camden DS services: health check carried out by clinicians, well-being check by carer support workers. All employed by the carers centre in one team. Focused on 9 wards with the highest health inequalities. Learning/outcomes: Carers were referred to over 40 agencies as a result of the checks. Carers really valued the integrated approach, and being able to work through goals with their support worker. There was a high level of carers reporting poor well-being. For 67% of carers well-being did improve after the intervention. Key issues of concern identified in the checks were a number of people with high blood pressure, and carers who were not getting reviews for their medication, or taking their medication properly. This illustrates how many carers do not prioritise their own health. Partnership working through the project was successful, and the project spent a lot of time building relationships between voluntary and statutory sectors. Organisations made changes in their services in order to better support carers.

**Coventry LINK:** The voluntary sector has played a big part in providing preventative services. The Contact and Connect service provided by Age UK Coventry is an example of good preventative practice as it provides pro-active contact with people aged over 85 to provide

information and support.
<b>Devon County Council:</b> The Council is working with its partners to co-design outcomes: (i) A new Devon Prevention Strategy, jointly developed with NHS Devon. (ii) Retaining independence for older people in the community and reducing reliance on health and social care services. (iii) Reviewing/safeguarding capacity targeted at residential and nursing providers to improve quality and reduce admissions from care homes to hospital. (iv) Promoting Assistive Technologies (including telecare). (vi) Providing additional support and information for carers. (vii) Reducing falls and preventing fractures. (viii) Implementing a Self Care strategy.
<b>Disabilities Trust:</b> In terms of early intervention, the Disabilities Trust has proved that if a person receives appropriate rehabilitation within a 6 month period of sustaining a brain injury, care savings of up to £1m can be made in their lifetime. This can only be achieved if structured and measurable support plans are in place and there is more joined up thinking in relation to the budget for longer term conditions, rather than one authority looking only at their contribution.
<b>Disability Cornwall:</b> Our Disability Information Advice Line (DIAL) service, with its outreach services, works very well, but it would only be possible in the statutory sector if services were 'de-territorialised'.
<b>Doncaster Metropolitan Borough Council:</b> In Doncaster there are specific teams that look at prevention and early intervention, including the wellbeing officers who look at low level needs providing early [intervention] to prevent crisis situations. If this service is used effectively by local communities, NHS and social enterprises there is considerable potential to save money for all parties as early intervention could maintain peoples independence, wellbeing and health, delaying or even preventing the need to access health or social care services. Adults and communities currently have five wellbeing officers who offer short term support to people who are low FACs (Fair Access to Care Services). The approach that is adopted is one of empowering people to access appropriate support services where these are required. In this way the service fosters a culture of self-determination.
<b>Durham County Council:</b> Examples of practice-based interventions: promote and extend the benefits of assistive technology/telecare in helping people to live safely and independently; reduce risks associated with long term conditions, such as dehydration, falls and other accidents and infections; reduce the risk of social isolation.
<b>East Lindsey District Council:</b> First Contact: clients identify their needs on a checklist; the agencies respond with short-term support (e.g. benefit assessments) putting money into clients hands, as well as giving longer-term support (e.g. fitting a smoke alarm).
<b>Future North West:</b> A good example of partnership working is that of Cumbria NHS Trust, who have set up a foundation trust based on partnership working. <a href="http://www.cumbria.nhs.uk/YourLocality/Transforming%20Community%20Services.aspx">http://www.cumbria.nhs.uk/YourLocality/Transforming%20Community%20Services.aspx</a> .
<b>Future Years:</b> A local authority and RSPCA organised dog walks, which proved very popular, reducing isolation and encouraging social interaction without the need to own a dog.
<b>Gentoo Group:</b> Our care and support services are person-centred with the aim of enabling the individual to live as independently as possible within their own home. A needs and risk assessment is completed with each individual, which is used to complete an Art of Living Plan with the service user, tailored to the individuals' needs, wishes, aspirations and opportunities. Thus service users are encouraged to discuss how their independence can be maintained in relation to access to services, community involvement, maintaining/developing social relationships, maintaining independence in their own home and achieving their aspirations. Need, goal, timescales, risks/barriers and progress are logged so that all staff are aware of the service user's needs and identify the required support mechanisms. Our Support Staff liaise with a number of other professionals such as Adult Services, NECA and Mind to



co-ordinate and ensure that care needs, dementia support and health services are meeting the needs of the individual to maintain their independence within their own home.

**Hampshire County Council:** In Hampshire we are investing in prevention services, for example:

- offering six weeks' free reablement care as standard to all those leaving hospital, which helps prevent readmission or a permanent move into more expensive residential care.
- piloting community-based reablement; the expansion of Extra-Care Housing, which has been shown to improve health outcomes, reduce the likelihood of hospitalisation, and reduce the likelihood of falls.
- the partnership work of our Older People's Wellbeing team, for example promoting the Trigger Tool. (The Trigger Tool is a signposting tool which brings together, in a single document, the contact details for organisations which may be able to assist someone in contact with older people, and who as a result may occasionally notice issues or problems. The Trigger Tool has been promoted through training with staff from county council departments, district councils, housing associations, pensions service and many voluntary organisations.).

**Kirklees Council:** Locally we have many examples of what works such as: (i) Schemes with Leisure Services that target people with identified health needs and link them to physical activity including dance sessions for people with hearing impairment. (ii) Library services offering a service to people who are housebound that has included benefits advice and social events. (iii) Activities for over 8000 people a week through targeted grant investment that is used to support and stimulate growth in the third sector and lever in additional investment-both volunteers and finance.(iv) We are carrying out a pilot with 3 groups and the new economics foundation to measure social return on investment. (v) A "Gateway" service that looks at tailored signposted, support (including health trainers and volunteers) to help people make informed choices rather than simply access "specialist" service.

**Learning Disability Coalition:** The Supporting People programme is an example of the success of prevention and early intervention for people with learning disabilities.

**Mears Group PLC:** Mears' care and repair service is improving outcomes for recipients of care. In areas such as Wigan where this service operates our care workers who regularly go into people's houses can identify hazards. By reporting a cracked tile or a loose fixture they are able to prevent falls. Repairs and maintenance staff time their visits to coincide with care workers so that the service user can be reassured that the maintenance operative is genuine. Our repairs and maintenance workers who work across all social housing stock are also trained to identify if they come across individuals in need of support or if they identify any safeguarding issues.

**Meeting of the National End of Life Care Programme Social Advisory Group:** Good examples of local level of preventative approaches leading to financial savings: POPPS (Partnerships for Older People Projects) project in Brent - early intervention and reablement meant that costs to whole system dramatically reduced.

**Merfield View Nursing Home:** The work of My Home Life.

**Middlesbrough Council:** An example of interventions that support these outcomes is Local Area Co-ordination, which has been piloted successfully in areas of east Middlesbrough. In Middlesbrough, a Personal Health Budgets Development Manager is in place to help drive the process of a closer link between Personal Budgets in Social Care and Personal Health Budgets. The "virtual ward" initially introduced by Croydon PCT, which mimics the structured approach to care within a Hospital, but which is delivered in the patient's home.

**NAIDEX:** Evidence re reablement/adaptation/environmental interventions considered to be strong.

**National Development Team for Inclusion (NDTi):** There is actually a wealth of evidence going back years about what works, and proving that prevention can be effective. From our own work this includes:

- Emergency admissions and bed days identified as avoided through POPP pilots (Poole POPP)
- Improvements in national indicators such as % people receiving care at home observed in POPP pilot areas (Poole POPP)
- Huge potential financial local savings identified (Dorset POPP)
- Wealth of positive, multiple & interrelated wellbeing outcomes for over 900 older people, described, logged and analysed quantitatively as well as qualitatively (Dorset POPP)
- (2001-2003): Two year National Evaluation of the pre retirement health initiative funded by DH's public health fund and led by the HDA - evaluating investment in a diverse range of interventions to promote healthy life style choices and behaviours in mid life as a key route to healthy ageing in later life (*The Gap Years: Rediscovering mid life as the route to healthy active ageing*. Bowers et al (2003). [http://www.nice.org.uk/nicemedia/documents/gap\\_years.pdf](http://www.nice.org.uk/nicemedia/documents/gap_years.pdf))
- (2002-2003) One year evaluation of phase two of the London Improvement and Development Programme for Older People's Services: Working with 12 London Boroughs, focusing on case finding / management approaches (including self management techniques) to supporting older people to remain or become healthy and self reliant. Contract with the (then) London Region of DH. This evaluation and development programme influenced the design / investment in the national POPP programme involving 29 pilots around the country.
- (2004-2005) Promoting independence and wellbeing for older and disabled people living in Tower Hamlets - evaluation examining the impacts of different investments made by the LA and its partners over this 2 year period, including case management approaches to enable older people to avoid hospital admissions and remain/become healthy and self reliant.
- (2004-2005) Moving Out of The Shadows (MOOTS) - promoting better mental health and wellbeing in later life - a national development programme focused on improving the participation and social inclusion of older people with a range of diverse mental health needs.
- (2006 to 2011): Local evaluations of two POPP pilots, in Poole and Dorset (evaluating investment in two different approaches to prevention within health and social care partnerships)
- (2009 to 2011): *Evaluation of the Department for Education's Short Breaks for Disabled Children Pathfinder Initiative*, looking at outcomes in places in England which had been the first to try to improve short breaks for disabled children.

Work by others includes:

- Long established work by the Audit Commission (Audit Commission - promoting independence and wellbeing for older people - [http://www.audit-commission.gov.uk/SiteCollectionDocuments/AuditCommissionReports/NationalStudies/OlderPeople\\_overarch.pdf](http://www.audit-commission.gov.uk/SiteCollectionDocuments/AuditCommissionReports/NationalStudies/OlderPeople_overarch.pdf)), social exclusion unit (Sure Start to Later Life: ending inequalities for older people. (2006) Social Exclusion Unit) and JRF on what prevention and promoting independence is about and outcomes that can be achieved.
- Financial savings identified through the POPP programme national evaluation
- Clear evidence that annual health checks for people with learning disabilities identify unmet health needs and lead to actions to address those needs
- Anecdotal evidence that employment can improve health and wellbeing for people with learning disabilities

**NCODP and ILN** ((Norfolk Coalition of Disabled People and Independent Living Norfolk): A model is the Norfolk Care Services Charter which seeks to create a vibrant care profession, fully integrated between the independent sector, voluntary sector, health and social services. This approach: attracts care workers who will be valued and can progress through a career structure; places social care and health care workers on a similar footing; improves understanding and communication between all the sectors; creates a 'profession' rather than disparate businesses; creates a one-stop shop for the service user: the first professional will

<p>assess need and suggest referral to professional services where appropriate.</p>
<p><b>NHS Blackburn with Darwen:</b> New services such as reablement and telecare have shown the extent to which preventative services can make a major difference in the lives of even very frail people, and close monitoring locally is now showing the levels of budget savings which can be achieved through these approaches. This is a key area for growth, which we are working on with others through the northwest ADASS/AQUA project. In relation to people with lower-level needs, approaches such as our Centre for Independent Living are key. And looking wider still, preventative work at a whole population level can help reduce need/demand, and also control costs: e.g. piloting of 111 number across Lancashire and a new Out of Hours service, major programmes to ensure that the right care is provided at the right time.</p>
<p><b>NHS Confederation:</b> The NHS Confederation briefing, <i>From Illness to Wellness</i>, gives details of different ways of delivering and joining up wellness services such as through health trainer programmes and single point of access models. Although measureable outcomes may not be achieved within a few years, the benefits to be gained in five and ten years' time will prevent existing health crises from getting worse and health inequalities widening. A Liverpool Public Health Observatory report reviewed different wellness services ranging from partnerships for older people projects to Job Centre Plus condition management programmes and The Homeless Games. The majority of services reviewed that considered costs were found to be cost-effective and have shown potential to bring a return on investment and save future costs due to ill health. Some initiatives not only made savings in care costs, but improved quality of life, enabling individuals to live independently.</p>
<p><b>North Yorkshire County Council:</b> POPPS (Partnerships for Older People Projects) evaluation. Telecare in North Yorkshire and telehealth in Barnsley.</p>
<p><b>Orbit Heart of England:</b> Within Orbit Heart of England, there are a range of services for vulnerable people including older persons, from Supporting People funded services for teenage parents to homeless hostels, very sheltered/extra care provision (called 'residential lite'), sheltered housing and home improvement agencies.</p>
<p><b>Parkinson's UK:</b> The most commonly referred to evidence of interventions comes from the Partnerships for Older People Projects which found the cost savings to the NHS, in terms of hospital admissions, from a variety of interventions such as falls prevention. However these appear to be the services that are cut first, or suffer lack of investment because resources have been rationed to those in most critical need.</p>
<p><b>Peers Engagement event:</b> There are lots of examples demonstrating the benefits of early intervention eg. Southwark Circles, Turning Point and the Timebank initiative in New Mexico with carers.</p>
<p><b>The Registered Care Providers Association Ltd (RCPA):</b> Already in place are measures that can reduce skin tears, static exercise systems and better seating to reduce falls, stronger transfer arrangements between home and hospital to reduce misdiagnosis and maladministration of medicines, the Gold Standards Framework for end of life care to prevent admission to hospital (funding for this in particular should continue).</p>
<p><b>Retirement Housing Group:</b> There is strong evidence that people experience good outcomes in terms of health, well being, prevention of loneliness and mental illness by moving to specialist housing ("Health improves and care needs fall when frail older persons move to more accessible accommodation Some social consequences of remodelling English sheltered housing and care homes to extracare" Wright Tinker et al in <i>Ageing and Society</i> Jan 2009). Mental, emotional and physical health of residents often improves, thereby reducing the burden on an ageing population (<i>National Health Service and Social Services RHG Position Paper</i> 2010).</p>
<p><b>RNIB:</b> Providing early emotional and practical support (including high quality information and</p>

advice) when there is sight loss can help individuals to manage their condition, ultimately leading to improved health outcomes The King's Fund (2010) How to deliver high-quality, patient-centred, cost-effective care. London: King's Fund; Pattenden J, Coulton S, Spilsbury K, Chattoo S, Cross B, Wadsworth V, Lewin B . Eye Clinic Liaison Officers and emotional support represent just two examples of early intervention services that provide this type of support. (ii) An evaluation carried out by the University of Liverpool demonstrates that the Emotional Support and Counselling services were both highly valued. By the end of their course of counselling users of the services exhibited a significant reduction in their level of psychological distress (University of Liverpool, 2010, 'Evaluation of emotional support and counselling within an integrated low vision service').

**Rotherham Metropolitan Borough Council:** Supporting People has developed an effective outcomes framework which supports providers to demonstrate how they are achieving outcomes for customers.

**Royal College of Nursing:** Two case studies: (i) End of life care Candice Pellett is a case manager district nurse and Queen's nurse working in an integrated community nursing team, Macmillan Nurses and GPs, Lincolnshire Community Health Services. (ii) Regular reassessment in practice: Vascular care for long-term conditions Evelyn Ryan is a District Nurse Team Leader at Coatbridge Health Centre, Lanarkshire, Scotland. Leg-ulcers in the house-bound have been dramatically reduced because two district nurses identified a need to treat these patients and introduced nurse-led clinics which work with nine GP practices in the town and the surrounding area. The team is committed to keeping people at home and are very robust at doing assessments.

**Staffordshire County Council:** We have a number of examples of effective preventative and early interventions: (i) Our Community Intervention Service provides an improved, less complicated service for people needing care in their own homes, developed in partnership between the County Council and the PCT and operating as an integrated model to improve the way we support people. (ii) Our commitment to the promotion of assistive technology to enable greater, prolonged independence for older people and disabled people. We have 50+ units which use the 'Just Checking' system in Staffordshire, to support people with dementia living in their own homes. (iii) We also have approximately 1500 telecare users and 12 flexi care housing schemes (diverting people away from). (iv) Our Personal Health Budget pilot, which has included anticipatory care through risk stratification and empowering patients to manage their own risks. Patients are risk stratified using a patient record system called EMIS Web and the EARLI tool which helps to identify patients who are at risk of hospital admission. Integrated case management is then put into place with case based discussion which involves the patient and their family to decide the best package of care for them.

**Standing Commission on Carers:** The Princess Royal Trust for Carers has found clear evidence of savings to the NHS (eg reduction in emergency admissions via A&E, shorter in-patient stays for people with long term conditions) where a Carers' Support Worker or Care Coordinator from the voluntary sector worked alongside the NHS and social care as appropriate.

**Sunderland Carers' Centre:** The outcomes of the joint working in the Sunderland area between the PCT, Adult Services, and Sunderland Carers' Centre (Voluntary Sector) to provide carers' breaks as preventative measures have been very successful particularly in helping carers to devote some time to their own health issues such as accessing gym membership or complementary therapies.

**Taunton and Somerset NHS Trust:** Good schemes include Rapid Access geriatric medicine clinics, Advance Care Planning in residential and nursing homes (a pilot has been run by Somerset PCT in Bridgwater), GP practice in Doncaster set up to provide good care in the nursing homes developed their own 'QoF' for NH patients, presented at BGS in Harrogate a few years ago.

**The Stannah Group:** Postponing entry into residential care by just one year through adapting peoples' homes saves £28,080 for example. Adaptations also save the NHS money in terms of emergency admissions and hospital bed days. We know that the average cost to the State of a fractured hip is £28,665, which is 4.7 times the average cost of a major housing adaptation.

**VONNE:** The work of Fresh - smoke free North East was considered to be good practice, where a strong partnership approach has delivered significant public health improvement. There are good examples of how "social prescribing" was working in some parts of the region (e.g. Sunderland) but even here, take up from GPs was patchy.

**West Lancashire Carers Sitting-in Service:** A perfect example of what is possible is available to see in West Lancashire for the last 18 years. A small service with a proven track record across all priorities exists on a small scale and could no doubt be rolled out nationally if resources were made available.

**Wirral's Older People's Parliament:** Wirral: a GP practice which identifies such people and has a trained, supported group of patient/befrienders/listeners who help the lonely and depressed get back on their feet. Also a successful local integration project for those with long-term conditions.

A cautionary note about examples of good practice was sounded by one respondent:

*One needs to be careful of evidence from particular services of success because of the potential for managers to promote their own services.*

British Association of Social Workers

## Working together to invest in prevention and promote wellbeing

A number of themes emerged in response to this question, with comments on funding and integrated working receiving the most mentions:



### Funding

Many respondents made the point that preventative services require adequate funding, with some suggesting ring-fencing or pooling funds:

*Ways of enabling a meaningful transfer of resources (no more than 5% from the acute health sector) to community based health and social care services would ensure that greater prevention and early intervention are turned into a reality.*

Telford and Wrekin Council

*The lack of pooled funding is one of the most significant barriers to early intervention and preventative services. People's needs are constantly changing and having separate funding streams does not cater for the flexible approach to care and support that is needed. Instead it results in the fragmented services that cost the overall public purse more.*

Turning Point

The ability of preventative services to save money was mentioned by some:

*What is also required is to look at financial support as positive investment in improving capabilities with the prospect of greater capability and independence in the future, and thereby to considerably reduce future support needs and*

*costs, as well as achieving results in better outcomes. Funding needs to support this investment principle, coupled with proper evaluation of results.*

Laing and Buisson

### **Sharing best practice**

A number of respondents commented that the financial case needs to be evidenced:

*In a climate of spending cuts, commissioners need to be given permission by national and local politicians to be able to invest to save. This research needs to be long term and accredited, and the Government has a responsibility to promote and support it. Without this, services will continue to prioritise response to crisis.*

Bristol City Council

Related to this point, some respondents suggested making best practice available:

*The greatest incentive to investment would be to centralise and pool evidence of outcomes and effectiveness to promote its value.*

Suffolk County Council

### **Clear strategic direction and integrated working**

A number of respondents raised the role of integrated services and effective joint working:

*Prevention services range from education, employment, housing, welfare, to public health initiatives as well as health and social care. This is why the social care White Paper should be a cross Government initiative which emphasises collaboration across the piece nationally and locally.*

Parkinson's UK

*We need to stop thinking about prevention and early intervention as a separate issue and integrate it into practice at all levels.*

Halton Borough Council

The new health and wellbeing boards received the most mentions for the drivers of this, with some also mentioning that the Joint Strategic Needs Assessment will underpin this:

*Health and wellbeing boards have a key role to play in managing prevention and early intervention as they have the potential to drive the whole range of local action on integration.*

West Berkshire District Council

*Health and wellbeing boards will be ideally placed to drive the prevention agenda if informed and committed to focusing on reducing inequalities and preventing further increases in poor health and premature deaths.*

Physical Disabilities and Sensory Impairments Partnership

*There needs to be a named individual, responsible for leading on early intervention and preventative services to ensure that all of the different services are bought together. This individual should sit within the health and wellbeing boards.*

Turning Point

Several respondents also commented on the need for clear outcomes to be agreed:

*Interlocking outcomes frameworks for the NHS, social care, and public health supported by quality improvement tools such as NICE Quality Standards have the potential to encourage greater integration of services and thus better connections between prevention services and health improvement programmes in the NHS and public health with the needs of social care users.*

National Institute for Health and Clinical Excellence (NICE)

*Effective early intervention and prevention measures which deliver improved health and independence for adults would also need to be a national cross-departmental priority with related outcomes measures applied at local policy, planning and front line delivery levels.*

Care & Repair England

## **Information**

Information, a recurring theme throughout this engagement, was raised by a number of respondents. There are two key facets to this. Firstly equipping carers and users with information on services and wellbeing. Secondly, enabling professionals to understand what services are available, so they can signpost or refer to users/carers as required.



*Use of community awareness campaigns, training programmes, literature, websites, etc. that promote self-help and self-care, as well as provide individuals and families with early information.*

SEPT NHS

### **The role of the voluntary sector**

Several respondents argued that voluntary organisations have a key role to play in achieving prevention (albeit in the face of cuts).

*There needs to be more effective information and awareness of, and easy access to, local earlier prevention opportunities. The voluntary and community sector needs to be supported to deliver on some of this and rewarded to encourage effectiveness and growth.*

Newcastle City Council

### **Training**

Training was raised by some respondents, to enable the social care workforce to identify prevention and intervention opportunities (eg care workers recognising hazards in the home).

*Provide training and mentoring for professionals, in particular GPs should play a key role in promoting healthy living.*

Leicestershire County Council

### **Preventative services**

Reablement was mentioned by a number of respondents as an example of a preventative service:

*Efficient and streamlined reablement services working very closely with acute hospitals remains an urgent priority for cost-saving across social services.*

British Geriatrics Society

*Prevention services can be very broad - and can encompass telehealthcare, reablement, community health services, and lower cost options like building community capacity to better support volunteers to provide low-level support for older and disabled people.*

Carers UK

Housing also received a number of mentions.

*Good housing is in itself a preventative investment. For example settled housing improves health and reduces the incidence of respiratory and other diseases. Housing associations deliver preventative services which can intervene early and provide the right packages of support to meet their needs before their problems become more severe.*

National Housing Federation

### **Eligibility criteria**

Although this area of the engagement did not ask about barriers as such, a number of respondents argued that eligibility criteria being set too high worked against effective prevention:

*In social care, the focus of funding on those with eligible needs means that universal services which support early intervention and prevention may be marginalised, while these services are often more cost effective in the long term.*

Hampshire County Council

*Amend eligibility criteria to enable longer contact with at risk service users.*

Fusion

## Changing culture and behaviour

On the specific issue of changing cultures and behaviour, a number of suggestions were made:

- Rewarding good practice (some also mentioned penalising bad practice)
- Championing/sharing good practice
- Strong leadership
- Training
- Understanding what different agencies and organisations offer
- Communicating the benefits of prevention
- Taking a longer term approach

*There is a need for joint training with partner agencies, co-working on shared projects, use of research and other examples of successful projects to change culture and attitudes towards prevention....Strong leadership is needed from Health & Well Being Boards downwards to encourage and reward preventative ways of working.*

Nottinghamshire County Council

Some other practical proposals were put forward:

- Good referral mechanisms with monitoring and feedback systems
- Making intervention and prevention part of any inspection and quality regime
- Community Development Workers to get partnerships working together
- *“Increasing cross-sector secondments between Local Authorities, PCTs and care providers would also help to forge a common language and understanding”* (Papworth Trust)
- Personal performance measures that are weighted towards prevention

Eligibility criteria were raised by a number of respondents:

*The only way to change culture... is to stop attaching money to the FACS [Fair Access to Care Services] criteria, and thereby enabling councils to provide services to people banded as having low or moderate care needs.*

Disability Cornwall

*The culture and drive for prevention is there but eligibility criteria have not allowed this to happen. However leadership and champions will be the drivers for change.*

British Association & College of Occupational Therapists

Some respondents felt that cultures and behaviour were not the issue:

*The RCN would suggest that it is limited funding, not cultures and behaviour that is impeding a more proactive and preventative approach to social care needs.*

The Royal College of Nursing

Others argued that this issue needs to be seen in a wider context:

*The challenge to culture and behaviour will require a much greater understanding of the wider determinants of health, particularly housing related needs, by social care and health care professionals but also be the general public. This has implications for the composition of Clinical Commissioning Groups...and for public health because residents will need to be nudged to recognise, at an early stage, the way in which their housing needs may change as they age, and the need for them to plan for and to financial provision for those changes.*

Thurrock Council

*The culture change needs to be not just in social care and the NHS: the principles of co-production see people as assets and part of the solution. Prevention and promotion of well being is a priority for all departments. So for example the impact of benefit changes should not be seen in isolation.*

Kirklees Council

## Payment by results

Fewer respondents commented on this issue than other areas of the engagement.

Some of the specific suggestions which were made were as follows:

- Paying by targets/outcomes
- Using 'Social Return on Investment' to quantify benefits
- Payment by results through a percentage of allocated funding
- Charge PCTs for every patient admitted to secondary care who could not go to a community hospital or hospital at home scheme due to lack of beds
- Local authorities rewarded with any budget savings made by PCTs
- Paying by outcomes through local 'Social Investment Schemes' when measurements show a reduction in more expensive services
- A system of accounting which considers costs of possible future outcomes at the point when choices are made

Some respondents argued that payment by results should include user-specific outcomes:

*Payments by results would have to be structured differently across health and social care. Within social care, services are put in place to meet a clearly assessed need, which has been jointly assessed with the customer, and where the outcomes have been jointly identified.*

Bury Council

A number of respondents highlighted potential risks involved with payment by results, arguing that this could lead to the wrong services and outcomes being focused upon:

*There is a risk that payment by results will lead to cherry picking of services by providers and a lack of investment in those with the most complex needs. It would be helpful to evaluate existing payment by results schemes and pilot other possible areas.*

Hampshire County Council

A number of caveats were suggested:

*Any allocation of price related to 'payment by results' should therefore adequately reflect the unrecoverable financial costs of service delivery. We are concerned that if the balance between the mandatory and incentivised*

*payments is wrong, providers would choose not to supply to local authority commissioners.*

United Kingdom Home Care Association

*The introduction of payment by results must not lead to any unintended consequences. For some services it is difficult to measure results, particularly where service users have complex needs. It must not lead councils and other commissioning bodies to divert funding to those areas where short term improvements are seen. This could result in smaller, specialist or high quality providers being pushed out of the market. The introduction of payment by results may make service-providers more risk averse if they are unwilling to test new approaches. It should be managed in a way that maintains and improves the quality of services.*

Action on Hearing Loss

One respondent argued that payment by results systems should be consistent across the health and social care systems:

*The introduction of Payment by Results for people with complex needs (including current pilots in substance misuse, the criminal justice system and mental health) could look at how the role of separate partners impacts on the outcomes achieved and how they should be paid for this activity. However currently different PbR models are being developed separately by the NHS and for the Work Programme. Without a payment system that integrates funding and outcomes, the necessary incentives to encourage providers to work with people with complex needs will not exist.*

Turning Point

A couple of respondents commented on programmes already in place:

*Pilots are already underway involving local authorities, housing associations and other providers, to test out ways to apply PbR to housing, care and support. As PbR is expanded into the care and support system, it is crucial that the Government must work with the breadth of the provider sector, to benefit from this learning and [...] ensure that future PbR models focuses care and support providers on the right outcomes.*

National Housing Federation

*Develop measurements for quality of life to enable payment by results. Work has started on this and the potential for applying a social investment model in Leicestershire to help people to maintain a healthy weight is currently being considered.*

Leicestershire County Council

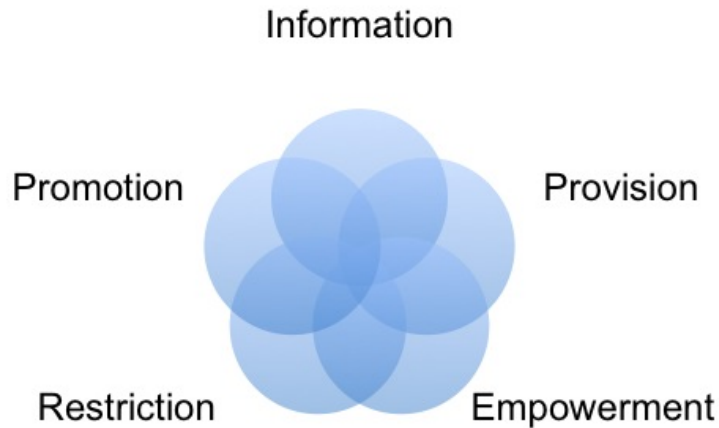
Finally, a few respondents argued that payment by results is not possible for preventative work:

*Payment by results could not work for this kind of work as it would be impossible to detect a successful prevention as the hoped-for outcome will, by definition, never occur. Interventions need to be long term: there are many examples of projects being funded, proven to be successful, then funding discontinued. This results in lack of stability for providers and service users.*

Regional Voices

## Encouraging individuals, families and communities to take responsibility for health and wellbeing

Responses to this question fell into five broad areas:



### Information

As we have seen in other areas, information received the most mentions. The type of information suggested can be broken down into three separate elements:

- The benefits of healthy living.
- Advice about what works/case studies.
- What services are available. One respondent suggested providing a one stop information shop about all available services. Another suggested providing local Well Being Officers who could signpost people to what is available.

### Promotion

A number of respondents commented in general terms about the role public health campaigns can play promoting healthy lifestyles.

*The 5 ways to wellbeing are very simple messages and could be used in national communication campaigns.*

Kirklees Council

*A recommendation of the Dilnot Commission was for a nation-wide awareness campaign to raise the profile of social care and encourage people to plan*



*ahead. This campaign could also be used to encourage people to take preventive action and raise awareness of preventive services.*

Age UK

One respondent suggested that publicity for prevention could be built into the operational plans for the new health and wellbeing boards, and local authority activity.

Respondents made a number of suggestions about appropriate channels to encourage and promote:

- Schools (the importance of encouraging healthy lifestyles from a young age was mentioned by several respondents)
- GPs
- TV (eg soaps)
- Other media

Several respondents stressed the importance of using accessible channels and formats:

*Accessible easy read information available in doctor's surgeries/ hospitals/ day-centres/ dentists/ opticians/supermarkets/ places of leisure.*

Bradford's Strategic Partnerships

Ensuring consistent messaging was also raised:

*This will require the co-ordinated efforts of all health and social care professionals to deliver consistent messages in an accessible manner, tailored to the needs and sensitivities of different groups within society.*

British Dental Association

## **Provision**

A number of respondents discussed the need to provide appropriate facilities such as:

- Sport and leisure facilities
- Health checks
- Community services such as classes and events
- Allotments

- Public transport
- Telecare and telehealth

Several respondents highlighted the role voluntary and community organisations can play in providing appropriate services:

*We need to pursue more projects such as peer mentoring, adult education, and schemes such as time banks, skill swap, and reciprocal help (the 'Circle' model from Southwark).*

Nottinghamshire County Council

Providing support for carers was raised by some respondents:

*As carers we do and are expected to do far more than any provider would, so when we ask for help or for vital equipment don't make us wait ridiculous times. We will get ill and end up not able to care for our families.*

Seldom Heard Groups – meeting with carers

A few respondents stressed the importance of preventative services being accessible both in terms of opening hours and also reaching out to different groups of people (eg those for whom English is not their first language).

Several respondents argued that promoting health should be seen in the wider context of people's life chances/circumstances:

*When people are supported to address the wider determinants of their health, such as improving their housing, social networks and maximising their income, they are more likely to adopt healthy behaviours.*

Regional Voices

## **Empowerment**

A number of respondents talked about the importance of empowering individuals to take more responsibility:

*For individuals, families and communities to take on more responsibility for their health and wellbeing they need to be empowered to do so, through involvement in decision making, for example, through consultation. This could lead to an increase in community led action for health improvement. Confidence and esteem of individuals and communities needs to rise as the incidence of*

*smoking, lack of exercise and poor diet often combine within the same communities.*

Durham County Council

One respondent suggested that local authorities had a key role to play in facilitating this:

*Harnessing the energy and creativity that exists in communities will not only increase population wellbeing but also be more cost effective for statutory organisations [e.g.] opportunities for people to be involved in decisions that affect their lives; facilitating more regular contact between residents (especially those who may otherwise be isolated); and helping people to gain the confidence they need to exercise control over their lives. With this approach the role of Local government will become increasingly one of providing infrastructure and support to enable individuals and communities to take control of their own wellbeing.*

Barnsley Council

## **Restrictions**

Some respondents suggested placing (further) restrictions on the following, for instance by making them more expensive:

- Alcohol
- Cigarettes
- Fast/fatty food

## Nurturing innovation

The following suggestions were made in respect of encouraging innovation:

- Promoting best practice
- Providing evidence
- The commissioning process (a couple of respondents mentioned the role of outcomes in this process, another referred to the National Market Development Forum)
- Encouraging micro/local providers (one respondent mentioned community budgeting)
- Funding pilots (one respondent suggested a 'Dragon's Den' approach)
- Rewarding/incentivising innovation
- Working together effectively
- Being willing to accept failure/take risks
- Providing local authorities with implementation funding
- Strong leadership

There were some specific suggestions around sharing best practice and working together:

- Master classes/improvement workshops for commissioners and providers
- *"Using stories to inspire and demonstrate how outcomes were achieved; illustrate the connections between better outcomes for people, savings for systems and community benefits"* (National Development Team for Inclusion)
- Establish a programme similar to 'Building Community Capacity' to link local authorities/community organisations together and share of practice.
- *"An online hub could be introduced to 'match-make' communities, providers, charities and social enterprises who are interested in collaborating to provide new services; showcase examples of innovative prevention practices; and develop the evidence base for prevention. NICE or SCIE could have a role in setting this up."* (Arthritis Care)

- A central forum/information exchange with commissioners (NHS and local authorities) to report on services/innovations aimed at prevention
- Introducing awards in social care eg 'Beacon Status' award

One respondent suggested using a local body already in place:

*The sector in Lancashire is considering how to work together and has formed a body called Third Sector Lancashire with a focus on communication and policy debate. If resourced this could be a good way of a bottom up and top down approach working.*

Voluntary Sector North West

Turning to specific comments made about piloting innovation, for some respondents this was about low level investment and a flexible approach:

*Innovation programmes with providers, with a low level of investment initially, will kick start some of that wider thinking linked to 'managing the market' and provide some of the necessary evidence to develop things further.*

Bury Council

*"Rapid prototyping" where you grow a model and test it as you go along can be more effective and flexible than more traditional pilots.*

Kirklees Council

Others favoured a more robust approach:

*Money should be released for pilot and innovative projects to encourage and drive creatively and to support a whole system approach to prevention... All approved initiatives should have strong return on investment measures.*

Cambridgeshire County Council

One respondent suggested using Social Care Bonds to fund pilots:

*In light of funding cuts, and looking at the perceived financial saving that will be made further down the line, the use of Social Impact Bonds as a way of raising the initial capital required for early intervention services can provide a clear innovation that encourages preventative services.*

Turning Point

# **Shaping local care services**

## Shaping local care services

### Engagement questions

#### **5. What are the priorities for creating a more diverse and responsive care market?**

- a. How would you define the social care market? What are the different dimensions we need to consider when assessing the market (eg type of provision, client group, size of provider, market share)?
- b. How could we make the market work more effectively including promoting growth, better information for commissioners (local authorities and individuals), improved quality and choice and innovation?
- c. Does there need to be further oversight of the care market, including measures to address provider failure? If so, what elements should this approach include, and who should do it?
- d. Looking to the future, what could be the impacts of wider reforms on the market? What possible effects would the following have on the market: the recommendations of the Dilnot Commission's report, the roll out of personal budgets and direct payments, and the drive to improve quality and the workforce?

## Defining the social care market

Answers to this question were **diverse but can be grouped into four broad themes**:

- Services required by individuals
- Types of care provided
- Types of providers
- Types of user groups

Defining the social care market from the **perspective of the individual** received a number of mentions:

*All the possible service responses, creative solutions, community, technologies and web based support mechanisms which help safeguard people, maintain well-being and support independence.*

North Yorkshire County Council

Other respondents discussed the market in terms of the **type of care provided, types of providers and types of user groups**, some or all of which overlap in some instances:

*We would define the market as providing services for: older people; adults with learning disabilities; adults with mental health issues; adults with physical disabilities and sensory impairment; supporting people, including vulnerable adults and young people over the age of 15 years.*

Rotherham Metropolitan Borough Council

*The social care market is not straightforward - for example there are traditional providers (e.g. profit or not for profit care organisations) but direct payments make it possible for people to employ individuals (e.g. relatives, neighbours etc) who may provide care on a much smaller scale. We would aim to allow access for people with LD to universal services e.g. leisure and transport. Similarly organisations that provide housing related support, advice and information, training, job coaching etc.*

Cambridgeshire County Council

*The Social Care market is any service provider, be it Statutory, Voluntary or Business Sector, who provide services to disabled people, older people or*



*carers around their care and support needs to enable them to be able to function in their daily living.*

Gateshead Access Panel

Some argued that the social care market should be seen in **very broad terms**:

*The range of providers of social care components of care packages, which could be individuals, groups or organisations, and be statutory, voluntary, private or informal and increasingly involves other services not traditionally viewed as social care but clearly deliver a social care function (e.g. libraries).*

Halton Borough Council

*There is a need to move away from a more rigid definition of the social care market to one which is wider, more holistic, preventative and personalised; here should be a greater emphasis on what organisations need to do to keep people in their own homes and push beyond the boundaries of traditional service provision...There is a need to maintain a broader range of providers which are not just local but include more specialist national providers...There also needs to be a mixture of different types of providers, for example, VCS, profit, not for profit.*

Durham County Council

*Need to go beyond traditional definitions and to consider the full spectrum of support from prevention, enablement to more specialist services.*

Bradford Metropolitan District Council

One respondent felt that the focus on traditional areas of care should not be lost:

*Important to focus on the traditional areas of adult social care - residential / nursing care, domiciliary care, and respite care as they will still continue to dominate social care services over the intermediate future*

St Helens Council

A few respondents commented on the **changing nature of the social care market**:

*Supply side is currently in a state of some flux. The sector is trying to push through a transformation agenda (personalisation) in times of tight budgets.*

Consumer Empowerment in Social Care event

*The social care market is constantly changing and developing in line with requirements. If personalisation is to be a priority it will be driven by service user demands and what they choose to purchase.*

Physical Disabilities and Sensory Impairments Partnership

A number of respondents made the point that the social care market is **fragmented and diverse**, with one arguing that a clear definition is required:

*The current social care market is largely made up of private sector providers. It can not be viewed as one cohesive whole but is rather made up of smaller sub markets/categories normally defined by provision (e.g. residential care, domiciliary care etc) and client group (Learning disability, older people etc). It is rare to find (in particular residential care) providers who work across client group boundaries.*

Thurrock Council

*The market is also significantly fragmented across different client groups and providers under these different service groups or types of care e.g. residential care and homecare do not see themselves as part of the same market. A clearer definition of social care is therefore required and publicised for people to understand what this relates to.*

Derby City Council

A handful of respondents **rejected the concept of a market in the context of social care**:

*The term market is overused, and inappropriate when discussing people.*

NELCS (North East London Community Services)

Some respondents deliberated upon how the concept of a market applies to social care:

*Care is a "social good", but it is increasingly not a traditional public service which is delivered and managed by the state - it is delivered by a market of public, private and third sector organisations, and purchased by a combination of state and private funds. The "social market" of care, therefore, can neither be managed like a public service, nor left to manage itself like a private market.*

Parkinson's UK

There were very few specific comments on the **different dimensions to consider** when assessing the market, and responses on this were diverse. Looking at client groups (including carers) was mentioned by a couple of respondents. Others raised the dynamics of the market such as diversity and unit costs. A couple argued that the market should be assessed in terms of quality rather than price.

*Dimensions to be considered include: diversity; capacity; unit costs, accessibility and flexibility.*

Middlesbrough Council

*The elements to consider when assessing the market should include type and size of provider, type of provision, the setting in which this provision is delivered, the client group and the eligibility of their needs, the geographical spread of provision, the market size and the market dynamics within each sector, for example mental health, learning disability etc.*

Turning Point

*Assessing the care market as well as type of provision and client group etc, you also need to consider how service users and carers rate those services, how user-focused they are, how much they engage and involve the people they work with and how accessible they are to working with the range of communities locally.*

Plymouth LINK (Local Involvement Network)

As we have seen, a number of respondents described the market as diverse and fragmented and one made the suggestion that it may need to be broken down into sub-markets:

*Need to establish what the market is and this might need to be broken down into different markets if the outputs/services /users are very different. Also need to identify who is in the market.*

Leeds City Council and Leeds CH Trust

Finally, several respondents made the point that any consideration of the market needs to include specialist services and providers:

*The White Paper should therefore state the mechanisms and processes that will be put in place to ensure the market has a place for and makes best use of specialist providers.*

Autism West Midlands

## Making the social care market work more effectively

This question attracted a great deal of comment, with a wide range of suggestions being made. These can be grouped into the following themes, with information provision being raised the most often:

- Information for users/carers
- Information for providers/potential providers
- Encourage small/new providers, stimulate competition
- More effective LA commissioning
- Working in partnership
- User involvement
- Pay proper cost of care

### Information for users/carers

As we have already seen, making **information available to users and carers** was a key priority for many respondents and this was also seen to be an effective driver for making the social care market work more effectively. A few also mentioned advocacy and brokerage in this context.

*More information about providers and access to services needs to be made available in a wider range of formats and locations. Service users should be signposted to information about a wide range of products and services available to them.*

Surrey County Council

A number of respondents commented that **quality ratings** were important to help users navigate the market, with, as we have seen in the chapter on quality, some arguing that the Care Quality Commission's star ratings should be reinstated. Others felt that a different system could be developed.

*The main issue with available information is for non-professionals trying to navigate the care system. Although flawed, the previous CQC rating system was easy to understand by service users and their families. Without replacing this quality rating system with something that is consistent across local authority*

*boundaries it is difficult for individuals to make informed choices about their care.*

Thurrock Council

*Service users and carers will need to have good unbiased access to quantitative and qualitative information about the kinds of support that are available to them at what price and which they in turn can comment upon. They should also have information that illustrates the kinds of choices that other people have made and the outcomes they have experienced. The emerging e-market platform can provide the tool to achieve this.*

Barnsley Council

### **Information for providers/potential providers**

A number of respondents also suggested providing information (eg data on customer preferences, market sizing information) to providers and potential providers. For instance one respondent suggested that the market could be made more innovative by transmitting information on consumer preference to the supply side more effectively.

*Existing data is not widely used or understood. Much which would make the markets work better is already available - it is not intelligently used.*

HC-One

*NHS bodies, local authorities and 3rd sector organisations to work together to share information about people's varying needs, so that this can be fed to providers for service development. During this process user involvement should be an integral part of this process.*

Coventry LINK (Local Involvement Network)

*Better information is key not just at a macro level but at a granular level - there is a need to really crack local data about need and choice available at a small town and large village area so that people and providers can see the real choices and opportunities available to local people with needs.*

Meeting with Plymouth City Council Directors of Social Care and Lead Cabinet members

The **Joint Strategic Needs Assessment** was seen to be one means of disseminating market information:

*Commissioners will require more information around the implications and demographics of the local population.....The JSNA and the Joint Health and Wellbeing Strategy will provide information for commissioners, enabling them to make fully informed decisions.*

Durham County Council

### **Stimulating the market**

A number of respondents highlighted the need to stimulate the market by encouraging **small and/or new providers**, both profit making and not-for-profit. Concerns about bureaucracy and regulatory costs were raised as these are seen to make it harder for small providers to compete with larger providers:

*Local authorities often have to rule small business out, because they can't meet the financial criteria.....Procurement rules need to simplify - it is difficult for smaller and less mature organisations to compete with larger nationals and the process is time consuming meaning that the diverse nature of the provider market can be diminished.*

North Tyneside Council

*The commissioning process needs to be proportionate and ensure that smaller organisations are not precluded by unnecessary bureaucracy.*

VONNE (Voluntary Organisation's Network North East)

There were a number of criticisms of **tendering processes** being inconsistent across different areas. And while there was praise of framework agreements, for some this was an issue:

*The current use of framework agreements will in my view eventually lead to a reduction in choice and capacity, as providers will be unwilling to open new branches on a speculative basis. It takes 6 to 9 months or longer to create a viable business.*

Westminster Homecare

Simplifying the tendering process was suggested by some respondents:

*A passporting system, like the CHAS health and safety standard, that would qualify any organisation certified for all local authorities, NHS and Care Quality Commission would be welcomed.*

VONNE (Voluntary Organisation's Network North East)

A number of respondents recommended providing **support for start-ups and/or small providers**, for instance financial and regulatory incentives, as well as business development support.

*New and evolving businesses need information, advice and support in relation around setting up and getting a social care business started including provision of funding to support this.*

Nottinghamshire County Council

There were also suggestions to **invest in pilots** to stimulate the market and encourage innovation:

*We feel that Social Services commissioning teams should be strongly encouraged to invest in pilot projects with small, locally based organisations. These organisations are best placed to understand the communities they serve and develop truly innovative services that meet real local need.*

Tameside LINK (Local Involvement Network)

A couple of respondents felt that **private equity** had a role in the developing the market:

*The unpredictable and short term nature of local authority fees a major barrier to securing private investment by both providers and investors. Aggressive and short sighted procurement strategies by LAs were cited as a key factor in this, as well as a fundamental objection to profit demonstration by private providers despite the necessity of this to attract investment. ...Removal of the CQC star rating system made it more difficult to demonstrate the positive impact of investment. All participants agreed on the importance of private investment - either to enable new entrants to get into the market, or to help existing providers to transform their operating model through infrastructure investment.*

Financial institution meeting

### **More effective commissioning**

More **effective local authority commissioning** was mentioned by a number of respondents, who argued that this could stimulate innovation and improve services.

The following suggestions were made:

- Having a more strategic approach to developing the market
- Being more responsive to local needs
- Not being driven solely by price – quality needs to be factored in
- Building strategic partnerships with providers and health authorities
- Stimulating provision (as discussed above)
- Involving users in the commissioning process
- Encouraging innovation

Some respondents argued that the changing focus of commissioning required different skills and a more strategic approach:

*The role of local authority commissioners will focus increasingly on shaping and stimulating the local market. In order to do so effectively they will need to have the right skills as well as a strategic approach that seeks solutions across sector boundaries.*

Age UK

*There needs to be more sophisticated commissioning that engages users of services and carers and also utilises the skills and knowledge of providers.*

British Association of Social Workers

A couple of respondents suggested providing training to commissioners:

*The Government needs to ensure that social care commissioners are better trained and incentivised to consider long-term cost savings, social and environmental impacts and the need to provide a wide range of choice, specifically for the most disadvantaged.*

London Voluntary Service Council

Some respondents argued that Joint Strategic Needs Assessment and health and wellbeing boards have a key role in ensuring effective commissioning and identifying gaps in the market:

*We strongly support the Joint Strategic Needs Assessment as a tool that can help to deliver targeted services for vulnerable and hard to reach groups in a community...it can inform the commissioning of services by CCGs and local authorities. In addition, it should encourage local innovation, reduce health inequalities and build a local market for services that are based on the needs of the local population. It is essential that Health and Well Being boards engage with third sector providers and local community groups in the JSNA process.*



VODG (Voluntary Organisations Disability Group)

*A robust Joint Strategic Needs Assessment (JSNA) needs to be in place alongside published commissioning intentions to inform market development. The JSNA should not just be a series of data and needs to be based around the health questions and priorities that need to be addressed locally.*

Halton Borough Council

### **Working in partnership**

Working in partnership – both across statutory services as well as involving providers and third sector bodies – was suggested by a number of respondents:

*Health and social commissioners need to take a proactive approach to market development in order to meet the growing demand for services. A positive and mature relationship between commissioners and social care providers is critical.*

Nottinghamshire County Council

### **User involvement**

The role of user involvement in developing more responsive and innovative services was another recurring theme:

*The involvement of third sector and social purpose organisations and their constituent members, in a truly co-productive way to design and commission services locally, to meet local needs, will help in the creation of a more diverse and responsive care market.*

Disability Cornwall

*In the Midlands user-satisfaction went up significantly after the commissioning board set up a user-led board (of 7 people) to help them with commissioning strategy and monitoring/evaluation.*

Radar

### **Paying the true cost of care**

Some respondents argued that for the market to operate efficiently, the proper cost of care needs to be paid.

*There needs to be a national culture shift and communication about the importance of quality and value for money in the commissioning of services.*

*We need to understand the true cost of services. At present it feels like the cheapest submission wins the contract which can cause problems.*

South Gloucestershire Council event

*Impossible for providers in home care to drive innovation because the margins are low, and LAs are resistant. Also why should providers risk a change in their business if there is high current demand?*

IPC focus group

## Examples of making the market work more effectively

The following examples were given:

<p><b>Devon County Council:</b> The Council has sought to shape the market for support and care services through the establishment of the Provider Engagement Network.</p>
<p><b>Meeting with Plymouth City Council Directors of Social Care and Lead Cabinet members:</b> They have invested in a provider site on the Devon Website to enable the sharing of knowledge, data and intelligence leading to better engagement with providers. They have gathered information at the market town/coastal town level and this is informing the JSNA and all commissioning.</p>
<p><b>Doncaster Metropolitan Borough Council:</b> Developing an eMarketplace (Doncaster is leading on the development of this in Yorkshire and Humberside) will grow the market.</p>
<p><b>East Sussex County Council:</b> East Sussex Support With Confidence scheme will help people to find a wide range of care and support services that they can trust – from people and organisations that have been vetted and approved on grounds of quality, safety, and training including personal assistants, gardeners, handymen and stair lift services.</p>
<p><b>Elderly Accommodation Counsel:</b> We are currently exploring with one leading employer, Legal &amp; General, a training event early in the new year which is designed to explore the way the company's staff engages with older customers but which also works through long term health and social care planning.</p>
<p><b>Hampshire County Council:</b> The County Council is already working, alongside Trading Standards, to set up a panel of independent financial advisers to enable self-funders to make appropriate decisions about their care.</p>
<p><b>National Care Forum AGM:</b> Example of market shaping/management: Shropshire Council owns land, Order of St John arranged PFI equivalent with Housing Association, who accessed capital (£60m) from the Housing Corporation. NHS Intermediate Care Unit is a sub tenant. Hospital is a separate entity, and owns the building. The fabric has made a big difference to the staff. They show Shropshire CC their books to assure them they are a reliable company; and Shropshire CC in return make sure fee rises are passed on in wages to staff.</p>
<p><b>Radar:</b> DPOs provide much-needed insight and expertise to local authorities about the local care market. For example, in the Midlands user-satisfaction went up significantly after the commissioning board set up a user-led board (of 7 people) to help them with commissioning strategy and monitoring/evaluation.</p>
<p><b>RNIB:</b> In Harrow, an e-marketplace (like eBay for care) has been supported and a start-up funded by the local authority (see <a href="http://www.shop4support.com">www.shop4support.com</a>). In effect Harrow has helped to shape the market and the marketplace. Providers are forced towards it and there is a self adjusting effect on prices (in the same way that eBay works). We hope that it has the potential to open up the market place - especially for special interest groups like ours.</p>
<p><b>Southend-on-Sea Borough Council:</b> Partnership is a specialist financial provider of products to Older People and has been working with a number of authorities (Northamptonshire, Essex, Bedford) to develop access to specialist financial advice from local advisers accredited by the Society of Later Life Advisers (SOLLA). Although there are no SOLLA accredited IFAs in Southend, staff within the Council and partners in residential and domiciliary care services, now proactively offer the opportunity to access independent financial advice to all older people arranging and paying for their own care.</p>
<p><b>Staffordshire County Council:</b> We have renewed the Staffordshire Compact and developed</p>

Third Sector Commissioning Standards to ensure that our commissioning practices are accessible and equitable to the full range of providers. We are also developing the local market through the Staffordshire Cares Purple Pages, which is opening the market place to a wider range of providers.

**Voluntary Sector North West:** Wirral Well is an example of how markets can be developed to create choice.

## Is further oversight of the social care market required?

Some respondents felt that current structures are adequate. But more argued that further oversight is required. Responses generally fell into three categories

- Greater financial regulation
- Strengthening the role of the Care Quality Commission
- General comments on the need to inspect services

Comments on **financial regulation** focused on monitoring the financial viability of large providers:

*It would be very helpful to have a requirement on the national regulatory body to work much more collaboratively with the local authority and health agencies to ensure compliance with regulatory requirements and hold providers to account in relation to financial viability.*

Nottinghamshire County Council

*In a similar way to the financial services industry, care home providers of a particular size could be required to hold sufficient capital reserves. A greater role could be given to the Care Quality Commission to request information on, and monitor, the financial accounts of large providers.*

Which?

While some felt that the Care Quality Commission could oversee this process, others expressed doubt about this:

*Regulating the viability of providers would represent good progress but we are not convinced the CQC has the expertise to analyse the functions of a PLC sized business or understand its sustainability.*

RNIB

*As part of the provider registration process there should be an assessment of business viability and Care Quality Commission (CQC) are best placed to co-ordinate this and review as part of its on-going monitoring and inspection regime.*

Halton Borough Council

But some sounded a note of caution about greater financial regulation:

*it would be highly disproportionate for the failure of a large residential care provider to lead to the economic regulation of the homecare sector. The problems of Southern Cross stemmed from unsustainable rent bills, falling bed occupancy rates and a drop in revenue from councils. .... The homecare sector is fundamentally different from the residential care sector. Care is carried out in a person's own home and not in a care home. Homecare providers do not own or rent properties.*

United Kingdom Home Care Association

*Key objective must be to avoid sudden financial failure and closure of a care home. ... only a handful close suddenly,... so changes must be proportionate and targeted.... Improved market intelligence gathering and local level plans, ....Southern Cross not really preventable.*

William Laing meeting

A number of respondents felt that the **Care Quality Commission's role should be strengthened** through greater enforcement powers and more resources:

*The Care Quality Commission's arrangements need to be more robust and its enforcement powers improved. It is too bureaucratic.*

Middlesbrough Council

*The CQC could be strengthened and work closer with local authorities, to enhance information sharing and reduce duplication of information. There also needs to be greater involvement of service users, for example, Experts by Experience.*

Durham County Council

*The CQC needs more staff and resources so that it can do more unannounced visits and inspections.*

Agewell Wednesday Forum

The Care Quality Commission was criticised by some respondents. Some felt it needed to work more effectively both overall and in partnership with local authorities, others argued for a more restricted role:

*There does need to be better oversight of the care market which could be achieved by improved partnership working between local authorities and CQC. The current slow response from CQC in the event of serious concerns and provider failure is a barrier to partnership working.*

Suffolk County Council

*CQC is not working. It is remote from local communities....and local commissioners and social workers have little faith in the CQC process. Local intelligence regarding quality is essential as is user and carer involvement in provider services. Oversight nationally needs to be restricted to learning the lessons of what works at a local level.*

British Association of Social Workers

A few alternatives to the current regulatory regime were suggested:

*Models of regulation used in higher education and banking could provide alternatives to the current system operated by CQC. The sector seems to compare badly to such sectors in using analytical and quality tools with which to verify standards are being met, and accountability.*

Parkinson's UK

*More oversight of the care market is definitely required and more openness about how the contractual levers can be used to hold providers to account and to minimise the risks to individuals within care settings. The contractual framework needs to ensure that all providers are providing a 'balanced score card' of evidence about the safety; quality; client feedback and staff skills and training.*

Cambridgeshire Community Services

*Although it is recognised that Personal Assistants enable greater choice and control for the individual the Council and its partners would welcome a basic registration and vetting scheme to ensure that vulnerable people are safeguarded.*

Bracknell Forest Council

A number of respondents commented on the need for inspections or more inspections to oversee the market. Some respondents felt that user-led organisations should have a role in this process. 'Mystery shopping', to understand the perspective of the user, was also suggested:

*Instead of unannounced inspections, commissioning trained volunteers to see what the quality of care is really like from the user's point of view - 'mystery shoppers'. These would need to be CRB checked and licensed by the monitoring body.*

Carers Union

One respondent commented on their local arrangements for overseeing the market:

*Rotherham already has comprehensive arrangements in place for this, via a database and “eyes and ears” initiative. There are also very good links between the Safeguarding and the Commissioning teams.*

Rotherham Metropolitan Borough Council

## Measures to address provider failure

There were relatively few responses to this element of the engagement. Most responding did feel there needs to be measures to address provider failure:

*[The consequences of the collapse of Southern Cross] were managed efficiently by the sector, demonstrating its capacity for emergency management. . It may be possible to strengthen this capacity. The care home sector's record of emergency management is excellent, and the result of a genuine desire to self-regulate.*

Barchester Healthcare

The following suggestions were made:

- Contingency planning by local authorities and Government
- Require continuity of business plan from providers
- Changes to insolvency and closure arrangements (a bond scheme triggered by insolvency suggested)
- Dismiss from local authority lists
- Memorandum of Understanding between providers

Underpinning these suggestions is the need to ensure service continuity:

*Each provider and local authority should have in place a resolution plan to ensure service continuity in the event of service failure. This would need to set out what factors would lead to the regime being triggered, a clear statement that the needs of care home residents should be given significant weight when deciding what option to use, protection of any upfront payment for care made by residents, and whether local authorities require additional powers or proactive*



*changes to the way care home operators are structured/monitored in order to ensure that the objective of protecting care home residents can be met.*

Which?

One respondent requested more clarity on the issue of provider failure:

*We would welcome clarification of the extent of our role and that of CQC in the event of provider failure due to quality or financial reasons.*

Hampshire County Council

## **The impact of wider reforms on the market**

A mixture of positive and negative responses were given to this question, although the positive outweighed the negative.

The following positive benefits on the market were listed:

- Give service users more choice and control (a number of respondents raised the impact of the right to change provider)
- Create more flexible and responsive services (one respondent argued that care pathways would be smoothed)
- Increase diversity
- Greater innovation

*The roll-out of Personal Budgets.....will inevitably create a more responsive, higher quality care market in response to individual commissioning, as well as through the use of pooled Personal Budgets by service users.*

Disability Cornwall

*The proposed reforms will stimulate competition to provide high quality affordable services, encourage working in partnership to achieve this, drive improvements in service delivery, reduce public expenditure in the NHS and residential care provision, accelerate changes in attitude towards planning for comfortable independent living in later life, and improve public perception of care services for the elderly.*

London Rebuilding Society

*Users and carers would be more confident in rejecting poor services. An easily accessible directory of services and activities would make it easier to look around. The public must be encouraged by a better trained workforce, to look beyond the traditional domiciliary care for a more fulfilling package of supports. More successful preventative services will ensure a longer active life and higher expectations of disability and ageing.*

Wirral's Older People's Parliament

*Rapid development of innovations currently slowed by poor commissioning, such as development of assistive technology and 'hospital hotels'.*

Barchester Healthcare

But some respondents raised concerns:

- Services becoming more costly
- More difficult for smaller/user led organisations to compete
- Risk of market fragmentation
- Less innovation
- The market will be challenging to regulate
- Too much responsibility being placed upon individuals

*The implementation of the Dilnot recommendations could lead to higher costs for local authorities and a destabilisation of market.*

Surrey County Council

*The recommendations of the Dilnot Commission would have considerable impact on the market..... the cost of taxpayer funded care will increase.*

Hampshire County Council

Turning to the Dilnot reforms in particular (the practical implications of which are discussed later on in this report), some respondents made the point that it would not be possible to have different costs for council and privately purchased care:

*Implementation of the Dilnot proposals together with shift to e-market place environment will make it difficult to sustain separate markets and prices for council purchased care vs privately purchased care.*

Hertfordshire County Council

Some respondents commented that support would be required for both providers and commissioners as the market changes:

*Providers will need to gain insight into processes and principles and be able to adapt accordingly. Support in particular will be required for smaller voluntary and community providers who have less resources and infrastructure to be able to compete against the larger providers. In many local communities these groups form the bedrock of services for people who need social care support.*

Cambridgeshire County Council

# **The role of financial services**

## The role of financial services

### Engagement questions

#### **6. What role could the financial services market play in supporting users, carers and their families?**

a. In the current system, what are the main barriers to the development of financial products that help people to plan for and meet the costs of social care?

b. To what extent would the reforms recommended by the Commission on Funding of Care and Support overcome these barriers? What kinds of products could we see under such a system that would be attractive to individuals and the industry?

c. What else could the Government do to make it easier for people to plan financially for social care costs?

d. Would a more consistent system with nationally consistent eligibility criteria, portability of assessments and a more objective assessment process support the development of financial products? If so, how?

e. Would the reforms recommended by the Commission on Funding of Care and Support lead to an overall expansion of the financial services market in this area? How would this affect the wider economy?

f. What wider roles could the financial services industry play? For example, in:

- raising awareness of the care and support system?
- providing information and advice around social care and financial planning?
- encouraging prevention and early intervention?
- helping people to purchase care, or purchasing it on their behalf?
- helping to increase the liquidity of personal assets?

## Barriers to the development of financial products

Responses to this question (and indeed the whole priority area) focused much more on the consumer rather than the supply-side. This is probably partly because very few financial service providers took part in the engagement.

From the consumer perspective, a wide number of barriers were raised:

- Unwillingness to plan for the future
- Lack of understanding of their potential care needs
- Perception that care is the responsibility of the state
- Mistrust of financial services
- Cost/lack of funds
- Complex products

**An unwillingness to plan for the future** was seen as a significant barrier, with some respondents drawing comparisons with pension provision:

*Many people do not wish to think about the future and a life where they may be ill, old, infirm or suffering from dementia. Given that, how they might pay for care further down the line is not likely to be uppermost in their thoughts.*

Middlesbrough Council

Linked to this, some respondents felt that people had a **lack of understanding of their care needs**:

*People may....not anticipate future care needs until the need occurs at which point purchasing insurance may be financially unviable or impossible to purchase.*

Durham County Council

Some specifically talked about **the perception that the state will provide**:

*Culturally people have prior experience that this is the responsibility of the state.*

London Borough of Richmond Upon Thames

The perceived **poor image of the financial services sector** is a thread which ran throughout responses to this engagement. This issue was raised more than any other

in response to this question. Some argued that the sector as a whole has a poor reputation, others raised examples of mis-selling such as equity release plans:

*Many people had doubts about the role of the financial services sector offering private social care insurance. Doubts were based on perceptions about the ways insurance companies currently operate and concern about the affordability of insurance.*

Agewell consultation event

The cost of products was also seen to be an issue, with several respondents commenting that the current financial climate means that people are less likely to have the funds to spare. Complexity was also raised:

*The industry will still need to address the complexity issue and convince a sceptical public that long-term care products are good value for money.*

Bupa

Turning to providers, respondents raised the following issues:

- Concerns about profitability
- Poor potential take-up
- Uncertainties about funding/funding frameworks
- Unpredictability of risk
- Complexity and bureaucracy

These factors were seen to make it difficult to price products:

*Local authority assessment and eligibility criteria create an uncertain environment for care insurance, making it difficult to price and market products...It would be important for the state and private sector to work together to overcome these problems.*

Association of British Insurers workshop on information/advice

*There is too much uncertainty for the financial sector to take on the full risk. There is currently no cap on the amount an individual could have to spend on care, an insurance payout could be extremely large.*

Kent County Council

For a handful of respondents, financial services providers simply have no place in the provision of social care:

*R&RA have serious misgivings about the financial sector being more closely involved in giving advice or information on social care awareness and planning. The recent examples of mis-selling spring to mind.*

The Relatives & Residents Association

A number of respondents raised concerns about certain groups being excluded from financial services provision, for instance people with long term conditions such as a disability, those on low incomes, and those with mental health issues:

*Privatisation on this scale would not favour those with long term health conditions or people born with disabilities.*

Physical Disabilities and Sensory Impairments Partnership

And the possibility of discrimination was also raised by a couple of respondents:

*People who are more likely to experience higher care costs, such as HIV positive people, may be excluded from some financial products and thus not be able to plan so effectively for their future. Government needs to ensure that people with protected characteristics are not discriminated against by any new system and are able to plan for a healthy and well supported older age.*

The National LGB&T Partnership

A number of respondents suggested that there may be a role for voluntary organisations in the provision of financial products:

*It would also be worth considering how voluntary sector financial organisations such as local credit unions could assist in encouraging people to save for future care needs.*

Cambridge County Council



## The impact of the Dilnot Commission's proposals

Most respondents who addressed this question felt that the recommendations of the Dilnot Commission would overcome the barriers to the development of financial products to meet the costs of social care, either wholly or partially.

Providing clarity to both individuals and financial services providers was mentioned most often.

*The added certainty provided by a fixed cap will present the financial services industry with a massive opportunity to develop products to help people plan for this contribution. People would feel less threatened to 'hide their assets' to avoid paying social care fees.*

Surrey County Council

*The reforms would make a significant difference. A range of products exists in countries through Europe and elsewhere that would need only minor adaptations to suit the post-Dilnot White Paper world.*

Barchester Healthcare

*The recommendations of the Dilnot Commission go some way towards mitigating the effect of these barriers, In particular they have been widely welcomed for setting out a clearer offer between the state and individuals about current liabilities for care fees. This alone would help the general public understand the care system better and plan ahead.*

Age UK

A few respondents also mentioned that the reforms would increase the awareness of the need to plan for future social care costs, help shift responsibility to the individual and create a fairer system.

Some respondents felt that the Dilnot Commission's proposed reforms would not address the barriers because of confusion about the cap. Splitting out care costs and 'hotel' costs was also raised:

*This does not provide the clarity over total costs that an individual may face.. it is disingenuous to separate the two elements.*

Bupa

There were a couple of comments about whether the level of the cap would encourage individuals to save and stimulate the market.

A few respondents remarked that the reforms do not address the fundamental lack of trust in the financial services sector which is perceived to exist. Others made caveats about the importance of independent advice.

Several respondents made the point that care should be state funded. But, as we shall see in the next chapter of this report, among some there was an acceptance that the Dilnot Commission's reforms are the best offer on the table:

*RCN members prefer a state funded, rather than private insurance system (only 6% of members who responded to a survey supported this option). However, the RCN recognises that the Dilnot proposals are the best chance of a solution to a long debated and now critical problem. The RCN would like to see political parties and stakeholders come together to deliver greater investment with the Dilnot blueprint therefore.*

The Royal College of Nursing

Turning to the types of products which may be available under the new funding regime, there was not a great deal of comment on the types of products we would see:

The following products were mentioned:

- Annuities eg Immediate Needs, Disability Linked Annuity
- Convertible critical illness policy
- Insurance products
- Equity release
- Insurance products linked to pensions
- 'Care' savings accounts
- Long term care bonds
- Flexible life policies
- Interest only loans on property

*There is no one single product: need different solutions for people at different life stages.*

McKinsey roundtable on implications of Dilnot Commission report

A few respondents commented that pre-funded insurance policies were unlikely to have much of a role to play.

Some highlighted the need to develop new products:

*New products will need to be developed - the current range is limited (equity release, annuities, care home fees policies), expensive and complex and unattractive to older people and their families.*

Newcastle City Council

One respondent suggested that direct payments could include an allocated amount to pay for an insurance policy.

Some respondents focused on the product features, with a handful calling for the elements set out below. These calls were linked to general concerns about protecting consumers under the new system.

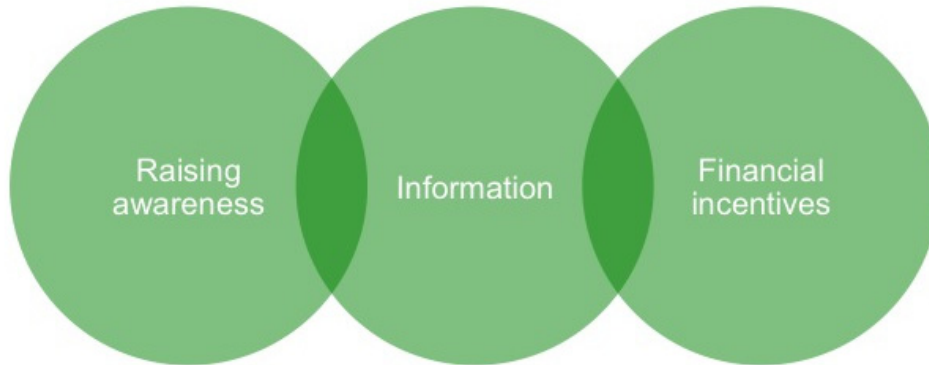
- Standardised policies
- National eligibility for insurance
- Good financial return
- Not have to pay commission

*If you do move to an insurance-based system, there needs to be clear, unambiguous nationally set criteria for payouts We do not want a system where insurers can use ambiguous wording in policies as an excuse not to pay out.*

North Notts Learning Disability Carers Network.

## What else should the Government do to make it easier to plan?

Responses to this question centred on three broad themes:



Raising awareness received the most mentions. Respondents made the point that people need to be made aware of the need to plan for the future. Some couched this in terms of encouraging individuals to take personal responsibility:

*Government has to make an unequivocal statement at the highest level that “care is not free and that people must make provision for cost of care in old age.”*

Partnership Assurance

*An awareness raising campaign would be a good start - stressing the fact that people are living longer and that most of us are likely to need some form of social care.*

Middlesbrough Council

A number of respondents mentioned the need for Government to play a role in the provision of information and advice, which was mentioned as a key part of the system by many respondents. The need to work with local authorities, the voluntary sector and carers was mentioned.

For some, this is about signposting or utilising what already exists:

*Ensure that individuals are aware of where information can be found through authoritative agencies: examples would be the increasing importance of First Stop as a source of advice about a wide variety of housing issues...harness the expertise of consumer advocates such as Which? and to encourage*

*consolidations like that between Counsel and Care and Independent Age, making it easier to identify definitive sources of advice.*

Barchester Healthcare

*To overcome the scepticism and distrust of financial institutions, brokerage should again be considered, potentially through the financial sector providing this support through trusted Third Sector bodies such as Age Concern or Citizens Advice Bureaux.*

East Lindsey District Council

But for others, this is more about developing new forms of information, for instance a national website.

*For the above market to take-off, information and financial advice will need to be developed for users and this information given its financial implications will need to be monitored and properly accredited.*

Tunstall Healthcare

A number of respondents suggested that as part of the information strategy, the Government should provide clarity about the exact cost of care.

Some respondents argued that the Government should provide financial incentives to encourage saving. Providing tax relief was mentioned most often, followed by general calls for incentives.

*It is worthwhile considering whether to have tax-breaks for products - or at least ensuring there is no tax disincentive associated with planning for care costs....Adding to the ISA allowance for retirees or having a care ISA.*

Association of British Insurers workshop on financial products

As we have seen, many respondents believed that the Government has a role in ensuring that financial products are properly regulated and fit for purpose:

*Tightly regulated, simple and easy to purchase with no small print clauses.*

East Riding of Yorkshire Council

A few respondents also mentioned that the Government has a role in stimulating the market.

## Would a more consistent system support the development of financial products?

Among the few who commented on this question, most thought a more consistent system will support the development of financial products:

*A more consistent, transparent...assessment process would support the development of financial products by enabling financial service providers to better predict the size of the market on a regional basis... making it more financially viable.*

Disability Cornwall

A couple of respondents felt that a more consistent system would undermine local control, while two others mentioned this being against the personalisation agenda:

*Possibly, but this consistency, or standardisation, goes against the thrust of personalisation and, to some degree, the Government's Localism Agenda.*

Middlesbrough Council

The need to acknowledge regional variations was raised by a couple of respondents:

*A national eligibility criterion, in theory, would offer a clearer and more consistent approach, but ignores the inconsistent demographics of health and wealth across the country.*

Papworth Trust

## Would the Dilnot Commission's recommendations lead to an expansion of the financial services market?

Among the handful of respondents who commented on whether the reforms would lead to an expansion of the financial services market, many thought it would:

*If the proposals are enacted this will stimulate the insurance and equity release market which will be good for the economy as a whole.*

Housing 21

Others were unsure or sceptical, citing the potential barriers:

*Not in the short or medium term....The critical factor here is that of trust. There will be a degree of 'chicken & egg' here - people will only take up products when they've been seen to work (which takes time), but services won't be offered if insurers etc don't see any potential 'buyers'.*

Bury Council

There were even fewer comments on the impact on the wider economy, and these remarks were disparate in nature. For instance two respondents discussed the increase in numbers of people saving and one pointed out that there will be a flow of capital to financial services providers.

## The wider role of the financial services industry

Most responses to this question focused on raising awareness, help with financial planning and providing information.

Raising awareness received a number of mentions, although several respondents stressed that Government and local authorities also had a role in this respect:

*They could raise awareness of the care and support system as this would benefit the financial services industry if more people chose to take out insurance.*

Durham County Council

*The financial services industry will clearly have a role to play in raising awareness, and provision of sound information from each insurance or product provider is essential. However, this will not replace the need for independent information from the Government, or for free money guidance to help people decide whether they need to engage with the financial services industry.*

Age UK

Information provision was also mentioned by a number of respondents:

*The financial services sector clearly has a role in terms of promoting suitable products and providing advice and information about care and support.*

Housing 21

The role of financial services in helping individuals with financial planning was mentioned by a number of respondents. A couple made the point that planning should be seen in the broadest possible sense:

*Greater industry involvement through promoting new products could also change the demand for financial advice. Planning for or obtaining care and support requires holistic advice and information, financial advice must be integrated with all the aspects an individual needs to consider: - Housing, Health, Care, Money and Rights.*

Elderly Accommodation Counsel

There were very few comments on the role of financial services encouraging prevention and early intervention. A couple of respondents made the point that



insurance companies could encourage prevention through lower premiums. Only one respondent substantively addressed the issue of purchasing care, commenting that there could be a brokerage role for financial services providers, as long as they did not have a financial interest in potential providers.

Turning to increasing the liquidity of personal assets, a number of respondents argued that this is key:

*Almost 80% of older people own their own home and hold more than £1.1 trillion of equity in their properties (The Financial Inclusion Centre, 2010). Accessing this money can be the solution to the funding crisis in adult social care.*

McCarthy and Stone

Others argued that equity release schemes should be not-for-profit, citing the existing work of Age UK, and developed to avoid the problems of the past.

A number of respondents made the point that there is a need to improve the image of equity release products as well as the quality of the products available:

*There is a need for good value, user friendly equity release products so older people are able to realise capital from their homes and use it to finance care and support. To date there are few suitable schemes that work favourably to the consumer. In our experience as an expert older people's housing provider, no products that currently exist are popular solutions for older people.*

Housing 21

As we have seen, a handful of respondents reject outright financial service providers having any role in social care. Other respondents counselled caution because of the poor image of financial services sector:

*Based on the deep seated lack of trust in the financial services industry...it may be better for them to play a very limited role and for information to come from a more respected national source.*

Doncaster Metropolitan Borough Council

More commonly, respondents suggested safeguards and proper regulation:

*Protective legislation and guidance needs to be in place before advice, information, advocacy and new financial / insurance products are offered.*

Bradford Metropolitan District Council

*Financial advice about care products should continue to be regulated. ...There is also a Government role for regulation of care fees products. ...these products are not suitable candidates for light touch regulation.*

Carers UK

A number said that any information and advice offered must be independent:

*Any private information and advice about social care and financial planning must be able to demonstrate its independence from any actual provision.*

Northamptonshire LINK (Local Involvement Network)

In this respect a role for the voluntary sector was suggested by some respondents, with Age UK and FirstStop both receiving mentions:

*It would be helpful if high quality financial advice on financial products could be provided through organisations such as Age UK that are independent of the financial sector and generally trusted by older people.*

Leeds City Council and Leeds CH Trust

A few other respondents mentioned the role of independent financial advisors:

*There would be an important role also for independent advice, either through Independent Financial Advisers, or through organisations such as the Society Of Later Life Advisers (SOLLA).*

Cambridgeshire County Council

One respondent suggested setting up a network of Independent Care Advisers:

*A network of Independent Care Advisers (similar in concept to Independent Financial Advisers) who could provide accurate, up to date, unbiased and independent information on the options available, including the financial options. Care decisions would then begin to shift from "distress purchases" to "lifestyle choices" and "actively managed decisions."*

TLC Group

# **The Dilnot Commission's Proposals**

## The Dilnot Commission's Proposals

### Engagement questions

**7. Do you have any other comments on social care reform, including the recommendations of the Commission on Funding of Care and Support?**

a. What are the strengths and weaknesses of the Commission's proposals in addressing the problems of the current system? What are the priorities for action coming out of the Commission's report, including in relation to other priorities for improvement in the system?

b. What are the implications of the Commission's proposals on other areas of care and support reform?

c. The Commission presented a range of options in relation to some of their recommendations, which would affect the balance between the financial cost to the individual and the taxpayer. These include:

- the level of the cap
- the contribution that people make to their living costs in residential care

What would be the implications of different options on the outcomes that the Commission hoped to achieve?

## Strengths and weaknesses of the Dilnot Commission's proposals

### Overall reaction

Although some expressed concerns about certain elements of the Dilnot Commission's proposals, the broad thrust of the recommendations were supported by almost all respondents.

*The system proposed by the Dilnot Commission is the fairest and most equitable system that has been proposed to date.*

London Borough of Barking and Dagenham

*We firmly support the spirit and thrust of the Dilnot Commission recommendations as it attempts to address issues of fairness and equity protects the interests of those who will be vulnerable for longer periods of their lives, ensures those who can pay should pay and challenges people to acknowledge that they will have to make a contribution from accumulated personal wealth....It is almost universally agreed that the current system of funding is unsustainable - something has to change. Government needs to be brave and take that first step.*

Jewish Care

*Workable proposals which promise sustainable care services for the future and clearly identify the balance of responsibility for the cost of care between the individual and the state.*

United Kingdom Home Care Association

*Overall, we support the recommendations.... [They] will go some way in preventing people from facing often ruinous care costs, support people to plan for the future and have access to the care they need wherever they choose to live. ... National standardised eligibility criteria would remove the uncertainty of access to care faced by many individuals. ...We strongly support the plans for a national information, advice and awareness campaign.*

Sue Ryder

*A much needed breakthrough in policy.*

Individual

While some respondents would prefer a state insurance model, the Dilnot Commission proposals were seen as being the best option on offer:

*Whilst I would ideally prefer a comprehensive state insurance model, given that such a model is not on the table, I support the Dilnot proposal, which at least protects people from spiralling care costs, permits forward planning and passes the simplicity test.*

Caroline Lucas, The Green Party

Where opposition was stated, this was on the basis that social care should be free at the point of delivery:

*Almost all service users consulted reject the Dilnot recommendations for the future funding of social care. They do not think that they offer an acceptable or sustainable solution to social care's chronic funding problems...Most think that social care should be free at the point of delivery, funded through progressive general taxation.*

Shaping Our Lives

## **Strengths**

The strengths of the Dilnot Commission's proposals were seen to be as follows:

- They are fair/equitable
- They provide clarity and reassurance to individuals
- Individuals will be better able to plan for their future
- They will provide more consistent levels of care (a number of respondents said they would end the 'postcode lottery')
- Sustainable funding
- They recognise the current underfunding of social care
- Rationalises assessments
- The focus on advice and information
- Greater transparency and clarity on social care funding
- The proposals are properly costed

- The emphasis on integration and prevention

*They all thought the current system is unfair and that the proposals make sense...As carers, we worry about our children's future care costs, this system would allow us to stop worrying about our children's care and enable us to plan for our own care costs. We think this would be a much fairer and clearer system of charging for care.*

Seldom Heard Groups – meeting with carers

## **Weaknesses**

The following weaknesses in the Dilnot Commission's proposals were raised, with funding receiving the most mentions:

- The current underfunding of social care is not resolved
- Setting the eligibility criteria at 'substantial' works against the preventative agenda
- Cost of implementing the reforms
- Complexity/bureaucracy of metering costs
- More people will be brought into the care system
- Affordability/workability of the cap (plus confusion about what is covered)
- What happens to self-funders in expensive care homes when funds run out
- The issue of quality is not addressed
- Provision for younger and/or working adults with care needs
- Involvement of insurance companies
- Regional variations are not taken into account (eg costs of care, property prices, current proportion of self-funders)
- Danger of a two-tiered system of care emerging
- The cap may act as a disincentive to unpaid/informal care
- Social care should be free at point of use

*Good as the recommendations are, they do not address the under-funding in the sector to pay for the true cost of quality care.*

Laing and Buisson

*Whilst we are supportive of the recommendations to move to a national eligibility criteria, entitlement must be at a level that enables people to live their lives. The Dilnot recommendations must not be used to ration support to provide basic care to those with the highest needs, a situation that is already developing as many local councils tighten their eligibility criteria.*

Learning Disability Coalition

*A two-tiered support system may emerge from these proposals; that only those with considerable resources can benefit from high quality care and support. It is imperative that the Government subsidised share of costs does enable individuals to have access to high quality care and support.*

The National LGB&T Partnership

*Capping of individual contributions to care....could see large increases in the number of people receiving support from local authorities who under currently arrangements would be self funding.*

London Councils

*For some, it will never be possible to plan for the onset of a chronic and long-term condition - and private insurance would never be an available solution for those with an existing care need. Provisions must be made for people in these circumstances.*

MS Society

*If the person's contribution to capped care is 'front-loaded', as the report seems to propose, what is to prevent someone unnecessarily purchasing very high levels of support to meet their needs?....This could result in the person quickly reaching the £35,000.00 cap and then becoming eligible for state funding - with expectations of support with which the state might not agree.*

Newcastle City Council

*The Dilnot Commission's proposals are still complex in some areas, for example on how accommodation costs are paid and the factoring into state entitlement assessments of informal care contributions.*

NHS Confederation



## Implications of the Dilnot Commission's proposals

Respondents generally focused on these areas when discussing the practical implications of the proposed Dilnot reforms:

- Standardisation of eligibility criteria
- Funding and resourcing the reforms
- Integration
- Impact on benefits

Taking each of these issues in turn, some of the respondents raised concerns about the impact of **standardising eligibility criteria** given the differences in the care available in different areas:

*Local authorities cannot be expected to provide exactly the same care package, because different services exist in different areas. Our experience suggests that [portability] affects a relatively small number of people.... Therefore the response needs to be proportionate to the scale of the problem, as creating a national assessment regime may have unintended consequences. We would suggest that an ADASS [Association of Directors of Adult Social Services] protocol whereby authorities agreed to accept each others' assessments may resolve the problem, without creating a national care system.*

Hampshire County Council

A number of respondents pointed out that local authorities have different eligibility thresholds. One local authority raised concerns about setting the criteria at 'substantial' (although, as discussed later in this chapter, several respondents believe the criteria should be set lower):

*The proposal to base national eligibility at 'substantial' would financially impact those Councils currently operating at 'critical' and additional transitional funding would be required to mitigate against the larger number of clients eligible for services.*

West Berkshire District Council

A couple of respondents argued that changing the eligibility criteria had implications for workforce training:

*Workforce development is critical to the reforms. Social care staff need to be equipped with the right skills and resources to cope with any changes to the provision of care. Two specific elements of the recommendations would have significant implications on staff: changes to the Fair Access to Care and the administration of tracking care costs.*

Surrey County Council

Taking the opportunity to reduce the bureaucracy involved with assessments was urged by one respondent:

*The Dilnot Commission's recommendation looks equally, if not even more complex system in terms of assessment and working out who pays. It will be important that clear and simple processes can be implemented in a reformed system that alleviate rather than exacerbate the delayed transfers that result from duplicative eligibility forms.*

The Royal College of Nursing

The **funding** of the reforms was raised by a number of respondents:

*Both the current system and the cap need to be funded - and that this would rise steeply in the future. The elephant in the room was how the reforms would be funded.*

Beyond Dilnot event

*There are substantial cost implications for all the recommendations and options but it would be disappointing if funding for adult social care is given a low priority. This would lead to continuing uncertainty and would deter both the insurance market and many individuals from making plans for their future care and support needs.*

Southend-on-Sea Borough Council

*The estimated additional costs to Hampshire County Council are in the range £65.8m - £106.5m, with one-off costs of £11.6m. This should be seen in the context of an Adult Services departmental budget of £310m. These estimates show costs well in excess of those estimated by the Dilnot Commission.*

Hampshire County Council

*The changes that are needed to reform social care quality and funding are transformational. There is already a precedent for funding transformational change via ring-fenced funding for example: Social Care Reform Grant for*

*personalisation and funding to local authorities for the transfer of public health to them from Primary Care Trusts under the Health and Social Care Bill.*

Alzheimer's Society

Some local authorities discussed the additional burden the reforms would put on them, both in terms of the **costs and resourcing** of assessments:

*Based on the number of estimated self-funders in Surrey, there could be up to as many as 7,802 new assessments required per year at a cost of £3.1m per year. This does not account for any additional costs associated with annual reassessments, which would have further implications.*

Surrey County Council

*A £35,000 cap would have workforce implications, in that it would lead to a significant increase in the number of people requiring a care assessment, ... plus training and IT systems, ... along with the proposed extension of the current deferred payment scheme ... has implications for capacity, as authorities could see a huge demand in the number of people for whom it would become worthwhile to approach their local authority for help. ... This transactional workload could be significantly reduced in respect of those clients on state benefits if the data sharing clauses in the current Welfare Reform Bill were approved.*

Kent County Council

A number of respondents made the point that the Dilnot reforms would help drive **integration**:

*The implications of the Commission's proposals should be an integrating effect with other parts of the system, to create a personalised approach to care and support which encompasses health, social care, education, transport, housing and employment services.*

Turning Point

While others commented that the impact on the wider care and support system needs to be thought through:

*Need to clarify a number of issues; the impact on the wider care and support system, including the need to improve the NHS social care boundary, especially Continuing Health Care funding and ensuring that reablement remains free of*

*charge. Implications for other relevant funding such as Carers Allowances, Disabled Facilities Grants and Supporting People Funding.*

St. Helens Council

One respondent argued that the charging frameworks for residential and home care should be rationalised to avoid incentivising people to go into residential care:

*Charging arrangements for home care would continue to be determined by local authorities, potentially creating an uneven playing field between home and residential care and the risk of perverse incentives for people to go into residential care. ...We recommend rationalisation of the charging frameworks for residential and home care.... Having one nationally determined policy on contributions for residential care and 152 different arrangements for the costs of care at home works would be a continuing cause of confusion.*

Derby City Council

Some respondents raised the issue of the impact on **benefits** such as Carers Allowances and Attendance Allowance, with some concerns expressed:

*Dilnot report suggests that a potential solution to meeting the needs of those people whose support needs are not substantial is to use the benefits system to offer financial support to those with lower support needs. ... [Need] a full debate around the upcoming changes to benefits such as Disability Living Allowance (DLA) - which are set to be reformed to reduce the number of claimants - in the context of social care. Without this debate, there is a risk that people whose needs fall below the threshold of social care eligibility will also be found ineligible for disability benefits too.*

Mencap

*Regarding the alignment of disability benefits to the adult social care system, ..., we would have concerns about some of the underlying principles.: There are valid concerns that this would signal a move away from the social model of disability to the medical model, which is a backwards step.*

Cambridgeshire County Council

*The Dilnot system will mean self funders in residential care who become "state funded" once the cap is reached will lose their Attendance Allowance (or DLA) at this point. These savings must go back into social care, and not (as*

*happened in Scotland upon the introduction of free personal and nursing care) back into the DWP budget.*

Parkinson's UK

*Anomalies within the system should also be addressed including Disabled Facilities Grants for children which are not means assessed.*

West Berkshire District Council

The potential impact of the reforms on informal care was also raised:

*If the providers of informal care think they can withdraw support as a result of the reforms, the economic and social impact could be significant. It could also put significant strain on existing public and private services. The Profession would suggest that further research on these potential behavioural changes (and their potential financial impact) would be useful, particularly as demographics start to change.*

The Institute and Faculty of Actuaries

## Implications of the different options proposed by the Dilnot Commission

### The level of the cap

A number of respondents discussed the level of the cap, with several commenting that £35,000 is the right amount.

*Broadly speaking, we feel that if a cap were to be introduced, capping contributions at £35,000 would be an appropriate balance between the costs to the individual and the taxpayer.*

Cambridgeshire County Council

A few respondents felt that £35,000 was too low and that the cap should be higher.

*The £35k cap may be seen as too low to bother insuring by consumers who may expose themselves to significant risk.*

Partnership Assurance

*We would be strongly opposed to the proposal of capping an individual's lifetime contributions.... Setting this cap at £35,000 as proposed would mean that virtually all care home residents would fall into state funding.*

Royal Star and Garter Homes

Others argued that the cap should be lower, or no lower than £35,000:

*The cap on costs should not rise [above] £35K and should be as generous as it can be in economically straightened times. The higher the cap less numbers of people benefit and the more catastrophic costs that the individual has to bear. There is always the potential for the cap to be reduced downwards as the economic situation improves, allowing the state to be more generous to those with long term health and care needs, as the preference for people with Parkinson's has always been a free at the point of delivery system of care.*

Parkinson's UK

*Setting the cap too high would, as the report makes clear, render it meaningless: so few people would reach it that the protection against the risk of high social care costs would be minimal.*

MND Association

*A higher cap would place greater burdens on individuals and on their carers.... A much higher cap would lead to a disproportionate impact across different parts of England with those in the North, more likely to lose a greater proportion of their assets which relate to housing assets.*

Care and Support Alliance

A handful of respondents queried how the cap would be calculated and spend recorded:

*There needs to be clarification on whether the costs of care are limited to just (permanent) residential, or would the cap be based on all types of social care, including preventative services.*

Bury Council

*Will people have been judged to have met the cap based on what they have actually spent on care or what their local authority expects them to have spent in line with their notional package of care? People who fund care themselves tend to spend more on care than local authorities so may well have spent up to the cap figure before they are deemed to have done so by their council. Will people who have needs below the national eligibility threshold but who spend privately on care be able to count this spending towards their cap figure? Who and how will individual spend data be captured and monitored, especially if services are provided by the 3rd and private sector?*

Midland Heart

The impact on regional variations in costs was raised by some respondents:

*The level of the proposed cap is a difficult judgement. Costs will vary considerably geographically and there will continue to be arguments over whether some services should be treated as "health" services and therefore "free" at the point of delivery.*

British Association of Social Workers

*We would ask Government to consider the merits of flexibilities on the personal cap to reflect regional care costs and demographic pressures.*

East Sussex County Council

Some respondents did not comment on the actual level of the cap as such, but argued that it should be set at a level which was not too generous to the wealthy, while remaining affordable to middle earners:

*Those with high levels of income and capital would benefit the most as the cap would entitle them to Government funding whilst the middle income levels and capital assets owners would generate the increase in contribution. We therefore urge the Government to find solutions to implementing the recommendations.... that are sustainable and reflect fairly on levels of wealth.*

National Association of Financial Assessment Officers

### **Level of contribution to accommodation costs in residential care**

Very few respondents commented on the actual level of contribution; discussion was focused more on the principle of contributing towards so-called 'hotel' costs.

Some were supportive of the recommendation:

*Contribution of the individual to their living costs in residential care will help to balance the cost more fairly between the individual and the taxpayer as living costs are not dependent on the level of need.*

Knowsley Metropolitan Borough Council

*The disaggregation of the care home fee will enable individuals and families, providers and commissioners to make informed choices about alternative models of accommodation and care.*

Meeting with MHA

Others felt that this approach could lead to problems. As discussed in the shaping local care services chapter, some respondents argued that it could cause confusion to individuals:

*There is the danger of people misunderstanding what exactly the 'cap' includes... 'Hotel' costs are outside the 'cap', so in practice the amount a person has to pay could be well in excess of the cap. This needs to be explicit for all concerned.*

Bury Council

Calculating and monitoring the cost of accommodation was raised by some respondents, as was the issue of deciding what should be included in the costs:

*The commission's proposals to separate out accommodation costs from social care costs although appearing simple in logical terms will be a source of conflict and...resentment. Incontinence products and aids to daily living, hygiene products, skin care and special dietary products are just examples of this issue. Time and energy needed to provide good quality care can be diverted by such matters.*

British Association of Social Workers

*As a private provider we are concerned to think a competitor could charge care at a high rate and reduce their other charges, thereby obtaining greater state funding - who will control this? How will we be assessed on the care element as meeting it - will there be another imposition of eligibility criteria and assessments which impede the process for someone at the point of crisis?*

Aylsham Manor care home

*General living (or hotel costs) will in a lot of cases be significantly greater than the £10,000 suggested in the recommendations (i.e. for a quality nursing home).*

The Institute and Faculty of Actuaries

The potential impact on care costs was discussed by a few respondents. Several respondents pointed out that self-funders currently subsidise the cost of residential care.

A couple of respondents argued against setting the figure too high:



*It would seem necessary that the figure chosen should not be entirely arbitrary, but should bear some relationship to both the amount that people would pay for their living expenses if staying at home and receiving domiciliary care, and to the relative costs of care and hotel costs within the cost of residential care. It must also be noted that if the amount set is too high, people will exhaust their own resources more rapidly and require local authority support.*

Hampshire County Council

Finally, a couple of respondents queried what would happen where people were unable to pay their accommodation costs.

### **Residential care threshold**

Most respondents who expressed an opinion on this, supported the proposed threshold of £100,000. A couple argued that it should be lower:

*[With] the increase in the assets threshold from £23,250 to £100,000, the funds we receive would reduce significantly as the majority of the clients properties are valued at less than £100k.*

Stockton Borough Council

*Threshold is too low and should be increased (the Hampshire Commission recommended raising the threshold to £50k).*

Hampshire County Council

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Finally, several respondents argued that the level of the cap, contribution to living costs and the capital threshold should be kept under review:

*There must be regular reviews particularly of the cap and tapered means test to ensure a fair level of contribution by both the individual and state is maintained.*

Papworth Trust

## Priorities for action coming out of the Dilnot Commission's report

A number of respondents argued that change in the funding of social care is urgently required and the Dilnot Commission proposals must be implemented:

*We see this as a once in a generation opportunity to set in stone a strong and lasting, fair foundation which will create clarity in terms of the role of the state and the individual in paying for Long Term Care. We would urge the Government to act now and implement the majority of reforms outlined in the Dilnot report.*

Housing 21

*It is clear that the Dilnot proposals are the most competent, credible and costed basis we have to reform a broken, unfair and overly complex system of funding care. Politicians from all parties must now seize the best opportunity in a generation to address these concerns.*

Midland Heart

*We do need a new model to fund care and it is unlikely that we will find a better one than that proposed by the Dilnot commission.*

Hertfordshire County Council

*If reform is delayed there is a risk that some of the momentum created by the Dilnot Commission's report - in tandem with other developments such as the Law Commission's final report on the future of adult social care - will be lost.*

Mencap

*We urge the Government to seize this opportunity to reform the system now, to tackle the ever increasing frustration and unsustainability of the current system. Nationally we have many older people living in isolation and situations that make them vulnerable, not eligible for any support. This situation will deteriorate further in the coming years unless there is immediate concerted action.*

Derby City Council

In terms of more specific priorities, all the recommendations of the Dilnot Commission received support from at least one respondent. However the following proposals received the most mentions:

- Introducing a cap on lifetime contribution to care costs
- Increasing state funding for social care
- A national system of eligibility and assessments
- National portability of assessments
- A national information and advice system
- Increasing the asset threshold for those in residential care
- Those entering adulthood with a social care need to receive free state support without being means-tested
- Zero cap for younger people who develop a care need
- Improving the integration of social care with other services
- The continuation of universal disability benefits

*Information and advice is absolutely essential - and a no brainer. Need to push ahead with that and other elements of Dilnot even if cap problematic - e.g. DPAs, Information, carers assessment, national eligibility criteria etc.*

Beyond Dilnot event

*Ensure equitable access to social care throughout England by standardising the means test and eligibility criteria.*

MND Association

*Strongly support entitlements and decisions on funding being taken at national level, by an independent national body. The Dilnot Commission provides a welcome framework on how to make the system more equitable.*

Parkinson's UK

*Capping the lifetime contribution to care costs and increasing the asset threshold for residential care... provides a basis for people to plan for the future at an earlier age and with greater certainty. This in turn opens the door for development of a greater range of housing options designed to meet the needs and aspirations of older people and which they can afford to purchase using their housing equity.*

Retirement Housing Group

*As recommended in the Dilnot report, there is a compelling need for the development of a new information, advice and support architecture for older people*

*and that a strategy should be developed, informed by current good practice, as the basis for a holistic, high quality service at national and local level delivered by a range of agencies. We urge the Department of Health to address this issue.*

Independent Age

*A nationally consistent system, with an assessment which follows the service user wherever they move, would ensure that when people access services their needs were considered in a consistent way wherever they lived.*

NHS Confederation

The proposal to improve carers assessments were welcomed by those who raised this.

The Law Commission's proposals to reform social care legislation were supported by all the respondents who mention them:

*The legal framework which underpins the social care system is outdated and in need of urgent reform. We welcome the Law Commission's recommendation to pull all social care law into one single statute. We believe it is crucial this recommendation is carried out.*

Mencap

As has been discussed above, while there were some criticisms about the details of the Dilnot Commission's proposals, implementing a new system of social care funding was urged by many respondents:

*Report is very much welcomed and offers optimism to secure a lasting solution.....The devil is in the detail and the proposals have flaws which are well documented. However the current economic climate does mean that the chances of any significant Government funding to support the reforms seem more remote as time goes on. It is incumbent on all those involved in the commissioning and delivering of personal care, including very crucially local politicians, to keep the pressure on Government to ensure reforms are funded and implemented.*

Suffolk County Council

# **Cross-cutting themes**

## Cross-cutting themes

A number of themes cut across responses to the 'Caring for our future' engagement:



Effective **information** provision to users and carers underpinned all of the priority areas, as did the availability of **advice** (including advocacy and brokerage).

As we have discussed in more detail in previous sections, respondents argued that information needs to be accessible, jargon free and available in a range of formats.

### Examples of good practice:

*The award-winning [www.payingforcare.co.uk](http://www.payingforcare.co.uk) is an impartial, comprehensive and consumer friendly website, which provides information on all aspects of care funding was launched this year in response to the recognition that in 2009 there had been 29 million Google searches for 'paying for care' and related terms.*

Partnership Assurance

*The Devon Advice Network of independent advice agencies promotes and improves advice services and provides clear routes to information and advice with guaranteed minimum standards of service: [www.askdan.me](http://www.askdan.me).*

Devon County Council

*Throughout the roll out of self-directed support (SDS) a range of support has been put in place for providers. This includes an on-line toolkit, a series of workshops, a provider champion group and quarterly personalisation provider briefings.*

Cambridgeshire County Council

The need to be able to compare providers was raised by a number of respondents, as this is seen as a way to ensure quality and make the social care market work more effectively. As we have seen in the quality and shaping local care services chapters, the loss of the Care Quality Commission's star ratings is regretted by some.

Information was also seen to have a role to play for service providers, commissioners and regulators, particularly around sharing best practice and innovation, as well as providing relevant market data.

Involving the **user** was another common thread across each of the priority areas, with some respondents also mentioning carers in this context. A number of respondents felt this would drive progress in improving quality, more effective personalisation and achieving better integration. Some respondents also mentioned carers in this context. Different degrees of user involvement were suggested, from eliciting user feedback using existing mechanisms to co-producing services with users.

Developing and training the **social care workforce** was raised in relation to the quality, personalisation, integration and prevention priorities areas. Some respondents argued that users and carers should be involved in providing training.

**Innovation** was discussed in each of the priority areas, particularly shaping local care services, prevention, quality and integration. Technology has a role to play – with telehealth and telecare being cited as examples. Portable user records is another innovation suggested.

*New supportive technologies offer opportunities on three fronts. First, they have the potential to transform the way health and care is delivered and managed, responding to the way people want to live their lives.....Supportive technologies like telecare and telehealthcare can promote health and wellbeing, support the management of long term conditions and sustain independent living, giving choice and control not only to older or disabled people but to their families and carers. ...Second, they have the potential to make health and care services more sustainable in the face of demographic change, delivering cost efficiencies, supporting systems integration and transforming the way people work....Thirdly, new supportive technologies have the potential to open up new markets in health and care. If we accept a greater demand for care, we have to transform the supply of care. There is a pay-for market in every other area of technology, and health and care should not be exceptions. The baby boomers*

*will not only take technology for granted in this space, they will want to buy it, for themselves, but before that, for their own parents.*

Carers UK

Local authorities and Government were seen to have a role to play in nurturing innovation, particularly around sharing best practice and in their approach to commissioning.

**Funding** was mentioned by a number of stakeholders in relation to each of the priority areas, both in terms of the investment required to achieve change, as well as the increase in funding required to improve social care:

*Mencap is calling for more investment in the system to help meet the growing demands placed upon it. Spending is currently relatively small; £16 billions, compared to £110 billions spent on health, and £180 billions spent on welfare.*

Mencap

*We have seen many attempts at reform over more than a decade, but most to little or no avail. Cross party talks are essential to form a consensus on this issue.... the Dilnot Commission's recommended £1.7 billion in additional public expenditure must not be seen as a stumbling block to reform.*

MS Society

Several respondents made the point that there was an economic case to be made for additional funding:

*We feel the Department of Health should work across Government to make an economic case for investment in social care. There is a case for the White Paper on social care to be sponsored across Government.*

Parkinson's UK

*Social care is usually discussed in relation to the need to reduce the cost, or burden, of care services to the state. Sense believes that this is a short sighted approach for two reasons: firstly the care sector plays a significant role in the economy of the UK and secondly failure to provide social care can have costly implications for other state funded services, most notably the NHS....The underfunding of social care also impacts on the ability of disabled people and carers to take up and maintain employment and so contribute to the economy.*

Sense



Finally, it is worth pointing out the extent to which the seven priority areas interlink. A vibrant and diverse market is seen to have a key role in achieving better personalisation, as does quality. There is a strong interplay between integration and prevention. And many respondents believed that the financial services market has a crucial role to play in underpinning reforms to the funding of the social care system.

We were asked by the Department of Health to look at three further areas in this section of the report:

- Carers
- Equalities issues
- End of life care

While the engagement did not explicitly pose questions on each of these topics, they are all of great relevance in informing the development of the Government's White Paper.

## Carers

Carers are defined in this report as anyone who provides unpaid support to family members or friends. How to define carers was queried by a couple of respondents:

*There is also the issue of the narrow definition of whether someone is or isn't a carer.*

CIRCLE

As we have seen in the chapter on quality, carers were seen by some respondents to be a key part of the social care system. A number of respondents stressed the importance of supporting carers:

*Need to support carers to stay in employment as they make great savings to the economy. Scarcity of jobs makes this hard.*

Peers engagement event

*Role of carers needs to be recognised and supported.*

Central Bedfordshire Council

*Better use of family members and carers by providing them with appropriate training and support to enable carers to provide better care.*

London Councils

One respondent argued that carers are key to the successful delivery of the Government's reforms:

*Carers are vital to the successful delivery of the Government's ambitions for both health and social care. They are key in developing and deploying community capacity and engagement and, in many cases, they will deliver a range of often complex care tasks which enable the patient or user to remain at home*

Standing Commission on Carers

To recap on what was discussed in the chapter on quality and workforce, the following was suggested to equip carers to improve quality:

- Carers need to have the relevant advice and information so they can make informed decisions
- Carers need to be recognised as key players in social care and listened to
- Carers need support (innovative and cost effective options for care and support should be explored)
- There should be training opportunities for carers
- Carers should be educated in the changing social care agenda
- Carers play an active role in shaping and developing local services and should be recognised as equal and expert partners in the design and co-production of a new generation of care services

It was also suggested that the role of carers in monitoring quality should be formalised by the Care Quality Commission as part of its regular monitoring process.

Some respondents discussed carers in relation to the preventative agenda, with calls for information, support and respite for carers:

*The importance of respite must be recognised when considering prevention. What might appear to be an unjustifiable short term expense can often avoid long term [care] if a carer can no longer cope. This might include all the costs of a family breakdown: poverty, homelessness, mental health issues, even police time in extreme cases.*

Disabilities Trust

*If carers were looked after more efficiently then the NHS would be saved thousands of pounds and we would be able to survive caring for our 'loved ones.' Lucky to be living in Devon where there are schemes to help, via the memory club etc. but there should be standards set throughout the country.*

Carer

Support and respite for carers were also seem by some to have a key role in promoting health and wellbeing for individuals and families.

Several respondents discussed the importance of effective integration from the carer's perspective, with involving carers in discharges from hospital being specifically raised:

*Within 'Caring for our future' and the NHS Forum engagement processes, we have a unique opportunity to address the current anomalies within the social care and health sectors and to improve the lives of carers and those they support. We see integration as a key theme, ending the frequent fragmentation between health and social care and integrating support around the individual and family.*

Standing Commission on Carers:

*The main reason for carers reaching breaking point is not lack of breaks, etc. but a frustration with bureaucracy. This is particularly acute for families where someone has complex needs, where the carer may be dealing with multiple statutory and non-statutory agencies and several departments within each.*

Carers UK

Turning to the issue of personalisation, there were concerns about the administrative burden this places on carers:

*Our research report in 2008, Choice or Chore, the first research into carers' experiences of personalisation, pointed to clear positive outcomes for families personal budgets..... However carers are also concerned about: · the burden of administration for direct payments (with 10% of respondents reporting they spent between six and fifteen hours per week on administration of direct payments and 24% receiving no support with being an employer)· leaving families at risk because of insufficient funds· a lack of good quality advice about legal responsibilities· the stepping back of local authorities from their legal responsibilities.*

Carers UK

Brokerage services were suggested as a way of tackling this:

*The funding of brokerage services will be essential particularly for the elderly and for carers who have a heavy caring responsibility and may find the navigation of direct payments and commissioning services onerous*

Sunderland Carers' Centre

As discussed earlier in this chapter, information, advice and user involvement are key themes cutting across this engagement. The needs and participation of carers were discussed in relation to all these themes:

*Recognising unpaid family carers as an important part of the workforce by giving them a seat on local health and wellbeing boards*

Carers Support Centre Bristol

Turning to workforce development, another key theme, several respondents argued that carers also had a role to play in this:

*Many carers are more than capable of training staff and supporting them with many care tasks and equipment but are not allowed to for insurance and other reasons.*

Crossroads Care East Kent

A number of specific issues were raised in relation to carers:

- The problem of ageing carers:

*We are particularly concerned about people with a learning disability who are living with ageing parents who are their sole carers.*

Mencap

- The impact of loss of earnings on carers

*Our Commission drew attention to the effects of loss of earnings during working age that carers face, which can leave them at risk of poverty after the age of 65, particularly since older carers cannot currently claim the full Carers Allowance as well as their State Pension. There is an implicit assumption built into the system that people over 65 do not provide care, which is not supported by the evidence.*

Hampshire County Council

- The need for financial products for carers

*There is very little information available about financial products for carer's. Mencap run some really good wills and trusts events, for carers of people with a learning disability. Offer this type of event to everyone that needs information and advice.*

Seldom Heard Groups – meeting with carers

- Better financial support for carers:

*Encouraging carers to provide support will save money. But the carers allowance is derisory - a better allowance could save residential care and costly agency care.*

*Look at how families and communities could be encouraged to look after their family members, e.g. tax breaks, better support, flexible approaches, allowing them to be paid from allowances if they are doing the work.*

STOIC and Carers Together

- Fears of asking for a reassessment:

*Currently carers are scared to ask for a reassessment of need if things change for the worse as they fear their personal budget will be cut, this pushes carers to breaking point.*

Seldom Heard Groups – meeting with carers

Turning to the recommendations of the Dilnot Commission, the proposals relating to carers' assessments were supported by those mentioning them:

*We support the proposals on changes to assessments especially the carers current support being excluded from the initial assessment of the person needing support and carers needs being assessed separately.*

North East Family Carers Network

Related to this, the importance of recognising a carer's separate needs was raised:

*Choice depends on carers having the right and opportunity to have a life of their own, respite care and breaks.*

Carers In Hertfordshire

As discussed in the chapter on the Dilnot Commission's recommendations, a couple of respondents raised concerns about the impact of the lifetime cap on unpaid informal care.

The Dilnot Commission's report raised the possibility of consistent treatment of housing assets for residential and domiciliary care. Including the value of the home in the calculation of assets was opposed:

*Carers UK does not agree that charging policies for domiciliary care should include the value of the home in the calculation of assets. Carers that we have consulted feel that this is a retrograde step. They felt that they had already given up sufficiently in terms of providing unpaid care to a significant level, some have given up work in order to care, and others felt that their home would be under threat particularly if they needed to continue living in the home after the person they cared for had died, securely, without the worry of being made to leave their home.*

Carers UK

Finally, there are three examples of best practice relating to carers which are listed in more detail in the chapter on prevention and early intervention:

- CIRCLE: Devon Demonstrator Site and Camden Demonstrator Site projects.
- Standing Commission on Carers: The Princess Royal Trust for Carers has found clear evidence of savings to the NHS (eg reduction in emergency admissions via A&E, shorter in-patient stays for people with long term conditions) where a Carers' Support Worker or Care Coordinator from the voluntary sector worked alongside the NHS and social care as appropriate.
- Sunderland Carers' Centre: The outcomes of the joint working in the Sunderland area between the PCT, Adult Services, and Sunderland Carers' Centre (Voluntary Sector) to provide carers' breaks as preventative measures have been very successful particularly in helping carers to devote some time to their own health issues such as accessing gym membership or complementary therapies.

## Equalities issues

Several respondents commented that care services and staff can fail to meet the needs of different client groups. As we have seen in the chapter on personalisation and choice, gay and lesbian residents are seen to face discrimination in care homes.

*Lesbian, gay, bisexual and trans (LGB&T) people often face harassment or misunderstanding ... or ignorance of their needs in [care] services so they often have to go back into the closet for fear of the reaction that they might get from care providers. There should be better training for staff focused on dignity and respect for other people regardless of sexual orientation, and more monitoring.*

The National LGB&T Partnership

*Care needs to be culturally appropriate - 'My father was in a nursing care home for one week. Even though he is Muslim, we came to visit on the first day and found that he was about to have lunch and there were pork Sausages on his plate.'*

Seldom Heard Groups – meeting with Pakistani Muslim women

While personalisation was seen to have the potential to benefit minority communities, concerns are raised about exclusion:

*Evidence suggests that groups protected in the Equality Act (2010) - including older and disabled people, mental health service users, Gypsies and Travellers and lesbian, gay, bi-sexual and transgender people - could potentially derive disproportionately greater benefit from the personalisation agenda but may be excluded under current proposals.*

Equality and Human Rights Commission (EHRC)

*Current services are not inclusive of LGBT users who feel unease and a struggle to get sensitive appropriate personalised services, and then only for those 'brave enough to be out'.*

LGBT Consortium meeting

In addressing the needs of minority communities, a number of themes emerged:

- The provision of appropriate services
- Information needs to be accessible to different communities

- Training of care staff
- The role of user-led support

*There are whole populations within communities that are poorly serviced, simply because the needs of the complete community are not meaningfully assessed before services are designed or commissioned....Many BME communities are effectively excluded from services at present because their particular needs are not understood, evaluated before or during service design and procurement.*

Turning Point

*There should be more culturally appropriate services available so that service users from BME background could have more choice to have the type of care that suits their needs better.*

Seldom Heard Groups – meeting with mental health service users from African & Caribbean backgrounds

*More training around cultural difference, ageism, dignity and respect.*

West Bromwich African Caribbean Resource Centre

*Personal assistants should be fully trained in supporting older lesbian, gay and bisexual people.*

Stonewall

*Brokerage and advocacy need to be funded to support people to access personal budgets and direct payments. User-led LGB&T organisations such as the members of the National LGB&T Partnership have an important role in this, to offer peer support, positive role models and frank discussions about safety and risk.*

The National LGB&T Partnership

The need to involve minority communities in the design of services was raised:

*Local authorities should work with black, Asian and minority ethnic communities (BAME) communities to support and develop culturally-specific services.*

Carers UK

*Good systems are patient/service user centred. This can be more difficult to achieve groups that mainstream service provision considers 'harder to reach', such as the LGB&T communities The LGB&T VCS is experienced at working with people with protected characteristics and responding to individual needs.*

The National LGB&T Partnership



While some respondents felt that improved market provision could meet the needs of minority groups, others felt that lack of economic viability made their needs less likely to be met:

*Growth in the market provision could lead to care explicitly for older lesbian, gay and bisexual people. Currently, there is a gap in the market for exclusive lesbian, gay and bisexual residential and communal home living. The Government could do more to support providers looking to support groups of people who are hard to reach or do not access the care system.*

Stonewall

*Minority community service users [are] least likely to have their specialist needs met as numbers of service users may be insufficient to make the development of specialist services economically viable at a local level.*

Regional Voices

The need to have an equalities framework in place to inform the commissioning and provision of services was raised by a number of respondents:

*In 2009 EHRC published its own report 'From Safety Net to Springboard' outlining vision for the future of care and support and the role it can play in promoting and safeguarding human rights, equality and good relations. The report was published before the Dilnot and Law Commissions reported, but it provides useful evidence equality and human rights considerations in the reform of future care and support.*

Equality and Human Rights Commission (EHRC)

*Department of Health should develop an equality and human rights framework to underpin commissioning and delivery of care services.*

Radar workshop

The importance of looking across the whole community in the development of Joint Strategic Needs Assessments and health and wellbeing boards was also stressed:

*Successful delivery of the equalities duty will require an integrated approach across all sectors and proactive approaches to working with community leaders and others to address gaps. We envisage health and wellbeing boards having an important role in engaging with minority groups in local communities and identifying strategies to engage them in the development and delivery of appropriate services and support.*

Standing Commission on Carers

Finally, the need for any reforms to the social care system to be subject to a detailed Equality Impact Assessment was raised by several respondents.

**Examples of good practice:**

*The Dekh Bhall Project: Is managed through a local Asian voluntary sector provider, is concerned with promoting training and employment opportunities for Asian people in the social care field, thus assisting social care providers working in Newham to provide more effective care to Newham's service users of Asian ethnicity. This project has been funded through the European Social Fund, SRB Green Street and Newham Neighbourhood Renewal Fund.*

Midland Heart

*For BME clients strong local community groups will help to gather and articulate their concerns and build confidence to express them. Middlesbrough has a strong Chinese community group with older people living in sheltered accommodation. The group has regular gatherings which can provide a contact point for feedback on experiences that help to inform quality.*

BECON (Black Minority Ethnic Community Organisations Network)

*Age UK Camden and LB Hackney have produced a 'checklist'...designed to support organisations measure their inclusiveness for lesbian, gay and bisexual service users and to tackle bad practice.*

Stonewall

## End of life care

Integration was seen as key to effective end of life and palliative care:

*We believe that the priorities of the health and social care sectors need to be better integrated at a national level to better support people with palliative and end of life care needs.*

Help the Hospices event

*If we get integration right in the final phase of life it will have beneficial effects across the whole adult social care system.*

National End of Life Care Programme + Social Care Advisory Group

It was argued that services should be based on the needs of the individual:

*Services should be available based on need not according to the condition you have or the particular care pathway/managers' priorities.... Social carers agree that something is needed but because your illness is not 'recognised' as needing palliative care (i.e. cancer), nothing (including respite) is available until you are so critical that emergency admission is required.*

National Council for Palliative Care 'Big Conversation'

Several respondents commented that the barriers created by the current funding system need to be addressed:

*As the Palliative Care Funding Review acknowledged, the current funding system for care creates barriers for professionals that prevent them from supporting a swift return to home from hospital for people at the end of life. Rapid access to high quality social care ensures that people get home from hospital sooner and avoid emergency readmissions.*

Marie Curie

*We are experiencing an increase in delayed discharges from our hospices [following] respite care as their social services care packages at home are being cancelled....Lack of integration at this key transition point leads to escalating, avoidable health costs as well as individuals feeling unsupported and concerned that the right package of care won't be in place when they leave.*

Sue Ryder

Communication barriers and duplication were also raised:

*The NEoLCP has a detailed analysis of what the social care workforce identify as barriers to integrated EOLC, mainly concerned with communication barriers and funding streams. Duplicate form-filling and multiple assessment systems are highlighted. These have implications for the wider health and social care network.*

National End of Life Care Programme + Social Care Advisory Group

A number of suggestions were made on improving end of life and palliative care through more effective integration:

- Adopting a single pathway approach
- Embedding integration through the development of a co-ordinator for people with palliative or end of life care needs
- Disseminating best practice
- More effective commissioning (it was suggested that clarity needs to be provided on the commissioning model for end of life care)
- Improvements in diagnosis and assessments
- Better access to records
- A standard application system

Prevention and intervention were also seen as key to effective end of life and palliative care, with respondents commenting that care planning needs to start much earlier in the care pathway.

*Prevention and early intervention [are] key to best practice in EOLC and achieving the outcome of a 'good death' - i.e one in which the dying person and their family are respected and supported in ways which are culturally appropriate and acceptable to them.*

National End of Life Care Programme + Social Care Advisory Group

*Prevention and early intervention with hospice and palliative care ... can extend choice, deliver a more personalised care experience and enable people to live well until they die.*

Help the Hospices event

The importance of appropriate training in end of life issues across the social care workforce was raised by a number of stakeholders:

*We recommend that end of life care should be a compulsory part of the curriculum for social care staff, both before registration and as part of their continuing professional development.*

Help the Hospices event

*Need to engage the mainstream workforce in end of life care...Specialisms are important but need to ensure that social care workforce have transferable skills and can operate across different disciplines.*

Meeting of the National End of Life Care Programme Social Advisory Group

Turning to the issue of personalisation, as we have seen in the chapter on this priority area, service users at the end of life were one of the groups identified as currently missing out. For some respondents, personalisation has real potential to improve end of life care:

*There is currently very low take-up of personal budgets amongst people at the end of life and evidence suggests that these need to be introduced early in the care pathway if they are to be attractive to people receiving palliative care. However, PBs hold out great potential for resolving problems of lack of continuity of funding causing disruptions in care.*

National End of Life Care Programme + Social Care Advisory Group

But others raised concerns:

*Hard for people receiving end of life/palliative care to have more personalised care because this is often only for short periods of time. In many cases, the emphasis will be on maintaining relationships within families.*

VODG (Voluntary Organisations Disability Group) Operations Directors Network

*Welcome introduction of personal budgets for people with end of life and social care needs, but not always appropriate for all people at end of life, particularly those with sudden diagnoses. Having to spend time understanding how to purchase care could cause undue distress.*

Marie Curie

As with other user groups, advocacy was seen as having a role in supporting users at the end of life:

*People at the end of life who do not have family/friends able to advocate on their behalf may be increasingly reliant on professionals listening to what they want and working on their behalf to put it in place....User organisations have a particular role to play in determining outcomes and designing services and should receive adequate financial support.*

National End of Life Care Programme + Social Care Advisory Group

At the Help the Hospices event, it was suggested that hospices are exemplars of personalised care:

*Hospices and their workforce provide a model for the development of personalisation and choice in care, and specifically provide a wealth of best practice in palliative and end of life care....Volunteer involvement is a key component of the personalised care that hospices provide to patients, service users and families.*

Help the Hospices event

Examples of best practice in end of life care (also listed in the chapter on integration):

- **St Michael's Hospice (North Hampshire):** Basingstoke End of Life Fast Track Service is an example of an integrated service working well for patients in the last 6-8 weeks of life.
- **Surrey County Council:** End of Life Care is run by health and administered by the Council.
- National End of Life Care Programme: **The NEOFCP has a bank of good practice case studies on its website.**

A handful of respondents commented on the Palliative Care Funding Review. Specific support was expressed for:

- Free social care for cancer patients in the last months and weeks of life

*[This] would also offer a cost saving for the NHS by enabling swifter discharge from hospital and preventing costly emergency readmissions.*

- Build up 24/7 community nursing in every Clinical Commissioning Group

# Appendices

# List of respondents

## Organisations

The following organisations submitted responses to the engagement:

360 Foundation  
Action for Advocacy  
Action for M.E.  
Action on Hearing Loss  
Action to Cure Kidney Cancer  
Adults with Learning Disabilities Services (ALDS) Forum  
Afiya Trust  
Age UK  
Alzheimer's Society  
Arthritis Care  
Asante Cultural Forum  
Autism West Midlands  
Barchester Healthcare  
Barnsley Council  
BASIS (British Autism Study of Infant Siblings) Network  
BECON (Black Minority Ethnic Community Organisations Network)  
Birmingham Advisory Council Of Older People  
Bitton Parish Council  
Bracknell Forest Council  
Bradford Metropolitan District Council  
Bradford's Strategic Partnerships  
Breakthrough UK  
Bristol and South Gloucestershire Local Involvement Network  
Bristol Care Homes  
Bristol City Council  
British Acupuncture Council  
British Association & College of Occupational Therapists  
British Association of Social Workers (BASW)  
British Dental Association  
British Geriatrics Society  
British Red Cross  
Bromley Experts by Experience  
Bupa  
Bury Council  
Cambridgeshire Community Services  
Cambridgeshire County Council  
Campaign to End Loneliness  
Camphill Families and Friends  
Care & Repair England  
Care and Support Alliance  
Care Quality Commission  
Carers in Hertfordshire  
Carers Support Centre Bristol  
Carers UK  
Carers' Union  
Central Bedfordshire Council  
Certitude Support



Challenging Behaviour National Strategy Group  
Chartered Institute of Housing  
Charteris  
Cherish Development  
Cheshire East Council  
Cheshire West and Chester Borough Council  
Chill4usCarers  
CIRCLE  
College of Optometrists  
Commission for Rural Communities  
Community Catalysts  
Complete Choice Care Services  
Coventry LINK  
COVER  
Crossroads Care East Kent  
Derby City Council  
Devon County Council  
Dimensions  
Disabilities Trust  
Disability Cornwall  
Disabled People Against Cuts  
Doncaster Metropolitan Borough Council  
Dorset County Council  
Durham County Council  
Ealing LINK  
East Lindsey District Council  
East Riding of Yorkshire Council  
East Sussex County Council Cabinet  
ecdp  
Elderly Accommodation Counsel  
Elders Council of Newcastle  
Endeavour Housing Association  
English Community Care Association (ECCA)  
Equality and Human Rights Commission (EHRC)  
ERYLINK  
Ewood Community Association  
FirstStop Advice  
Foundations  
Fusion  
Future East  
Future North West  
Future Years, Y & H Forum on Ageing  
Gateshead Access Panel  
Gender Identity Research and Education Society (GIRES)  
Gentoo Group  
GMB  
Green Party  
Guildford Soroptimists  
Halcyon Homecare  
Halton Borough Council  
Halton LINK  
Hampshire County Council  
Hartlepool Borough Council  
HC-One  
Herefordshire Council

Hertfordshire County Council  
Home Instead  
Housing 21  
Housing and Ageing Alliance  
Hull LINK (hosted by Hull CVS)  
Inclusion London  
Inclusion North CIC & members views  
Independent Age  
Independent Living Fund  
Institute of Commissioning Professionals  
Involve Yorkshire & Humber  
Jewish Care  
Kent County Council  
KeyRing  
Kirklees Council  
Knowsley Metropolitan Borough Council  
Knowsley, St Helens and Sefton LINK  
KPI Development  
Laing and Buisson  
Lancashire Care Association  
Lancashire NHS  
LCS Healthcare  
Learning Disability Coalition  
Leeds City Council/Leeds CH Trust  
Leicestershire County Council  
Leicestershire LINK  
Liverpool PCT and Member of Family Doctor Association  
Living Options  
London Borough of Barking and Dagenham  
London Borough of Barnet  
London Borough of Haringey  
London Borough of Redbridge  
London Borough of Richmond upon Thames  
London Community Resource Network (LCRN)  
London Councils  
London Rebuilding Society  
London Voluntary Service Council  
Low Incomes Tax Reform Group  
Macmillan Cancer Support  
Marie Curie  
McCarthy and Stone  
MCCH Society  
Mears Group PLC  
Medway Link on Behalf of a Medway Hindu Community Group  
Mencap  
Mencap and TIN  
Mental Health Foundation  
Merfield View Nursing Home  
Middlesbrough Council  
Midland Heart  
MIND  
Mind in Furness  
MND Association  
MS Counselling  
MS Research

MS Society  
My Home Life  
Napier Homecare  
National Assembly of Women  
National Association of Financial Assessment Officers  
National Care Homes Research and Development Forum  
National Careline  
National Centre for Independent Living, Radar, Disability Alliance  
National Development Team for Inclusion (NDTi)  
National End of Life Care Programme + Social Care Advisory Group  
National Housing Federation  
National Institute for Health and Clinical Excellence (NICE)  
National Pensioners Convention  
NCODP and ILN (Norfolk Coalition of Disabled People and Independent Living Norfolk)  
NELCS (North East London Community Services)  
NETS(work) Hosted by VONNE (Voluntary Organisation's Network North East)  
Neurological Alliance  
Newcastle City Council  
Newcastle CVS (Council for Voluntary Service)  
NHS Blackburn with Darwen  
NHS Confederation  
NHS Hertfordshire  
NHS Midlands and East  
Norman Street and Area Residents and Tenants Association  
North Bank Forum  
North Notts Learning Disability Carers Network.  
North of England Cardiovascular Network  
North Tyneside Council  
North Tyneside LINK  
North Yorkshire County Council  
Northamptonshire LINK  
Not a One Way Street Project  
Nottinghamshire County Council  
Nuffield Trust  
Oldham Council  
Orbit Heart of England  
Oxford University Hospitals  
Pain Concern  
Papworth Trust  
Parkinson's UK  
Parkinson's UK Canterbury Branch  
Partners for Inclusion  
Partnership Assurance  
Physical Disabilities and Sensory Impairments Partnership  
Plymouth LINK (Local Involvement Network)  
Premier Homecare  
Prison Reform Trust  
Radar  
RCPA (The Registered Care Providers Association)  
RDB Star Rating  
Regional Voices  
Rescare  
Retirement Housing Group  
Retirement Security Ltd  
RNIB

Rotherham Doncaster and South Humber NHS Foundation  
Rotherham Foundation Trust  
Rotherham Metropolitan Borough Council  
Royal Borough of Kensington and Chelsea  
Royal College of General Practitioners  
Royal College of Nursing  
Royal College of Physicians  
Royal Star and Garter Homes  
SARCP (Staffordshire Association of Registered Care Providers)  
Sense  
SEPT NHS  
Shaping Our Lives  
Sheffield City Council  
Sheffield LINK  
Shout Out  
Social Care Institute for Excellence (SCIE)  
Social Caring  
SOLACE (Society of Local Authority Chief Executives)  
Solihull Council  
Somerset County Council  
Soroptimist International  
Soroptimist International Gosport, Fareham & District  
South East Network of Disabled People's Organisations  
Southend-on-Sea Borough Council  
Spinal Injuries Association  
Spire Homes  
St. Helens Council  
St. Michael's Hospice  
Staffordshire County Council  
Standing Commission on Carers (SCOC)  
Stockton Borough Council  
STOIC and Carers Together  
Stonewall  
Sue Ryder  
Suffolk County Council  
Sunderland Carers' Centre  
SURG (Senior Urological Registrars Group)  
Surrey Care Association  
Surrey County Council  
Sutton's Health and Wellbeing Scrutiny Committee  
Tameside LINK  
Taunton and Somerset NHS Trust  
Telford & Wrekin ASCSC (Adult Social Care Scrutiny Committee)  
Telford & Wrekin Council  
The Aylsham Manor care home  
The Business Services Association  
The Care Forum  
The Glenmore Trust  
The Homecare Partnership  
The Institute and Faculty of Actuaries  
The National LGB&T Partnership  
The Relatives & Residents Association  
The Stannah Group  
Think Local Act Personal (TLAP)  
Thurrock Council

TLC Group  
Tunstall Healthcare  
Turning Point  
Unison  
United Kingdom Homecare Association (UKHCA)  
United Response  
VoiceAbility  
Voluntary Organisations Disability Group (VODG)  
Voluntary Sector North West  
VONNE (Voluntary Organisation's Network North East)  
VOX  
West Berkshire District Council  
West Bromwich African Caribbean Resource Centre  
West Lancashire Carers Sitting-in Service  
West Midlands Later Life Forum  
Westminster Homecare  
Which?  
Wiltshire & Swindon Users' Network  
Wirral's Older People's Parliament  
York People First

## Events

Feedback was submitted from the following events:

Association of British Insurers (ABI) Long Term Care Working Group meeting  
Association of British Insurers (ABI) workshop on financial products  
Association of British Insurers (ABI) workshop on information/advice  
Association of Chief Executives of Voluntary Organisations (ACEVO) roundtable  
Association of Directors of Adult Social Services (ADASS) funding reform plenary  
Adults with Learning Disabilities Services (ALDS) Forum  
Agewell consultation event  
Agewell Wednesday Forum  
Anchor Housing Trust meeting  
All Party Parliamentary Group (APPG) chairs meeting  
Apprenticeship Steering group meeting  
AVON and LA conference  
Beyond Dilnot conference  
Beyond Dilnot conference – a new future for social care?  
Building Community Capacity meeting  
Camden Provider Forum  
Care and Support Alliance roundtable discussions  
Care providers meeting  
Central Bedfordshire Council event  
Centre for Better Managed Health and Social Care conference - Caring for our future: quality and workforce  
Centre for Better Managed Health and Social Care event  
Centre for Intelligent Workforce (CfWi) conference  
Chartered Institute of Environmental Health (CIEH) conference – Environmental Health Offices - Guardians of Public Health  
City Bridge Trust Annual Conference  
Coalition for Better Health  
Community Catalysts events – Dudley, Nottingham, Oldham & Stockport

Connected Communities and Integrated service meeting – commissioning and community capacity learning exchange  
Consultation meeting with ADASS-NW/Learning to Care meeting  
Consumer Empowerment in Social Care roundtable  
Consultation in to the All Party Parliamentary Group (APPG) dementia report – response from Nuricia  
Crossroads Care meeting  
East Midlands Strategic Market Development event  
Eastern Area Committee meeting  
English Community Care Association (ECCA) roundtable  
Equality 2025 meeting  
Equity Release and Long Term Care dinner  
Financial institution meeting  
Halton Social Care Alliance meeting  
Help the Hospices event  
Health Services Management Centre (HSMC) workshop  
In Control & Association of Directors of Adult Social Services (ADASS) meeting  
IPC focus group  
Joseph Rowntree Foundation (JRF) equity release roundtable  
Kings Fund Future NHS Leaders Programme workshop  
Local Government Association Adult Social Care roundtable  
Local Government Association Adult Social Care roundtable  
LGBT Consortium meeting  
Local voluntary organisations meeting  
Macmillan Cancer Voices conference  
Making it real - Think Local Act Personal conference  
McKinsey roundtable on implications of Dilnot Commission report  
Meeting of the National End of Life Care Programme Social Advisory Group  
Meeting on Care Homes and Independent Monitoring Boards (IMBs) at Ministry of Justice  
Meeting with Bupa  
Meeting with Commissioners, Social Services, Plymouth Council  
Meeting with Directors of Social Care and Lead Cabinet Members  
Meeting with Kingston Council commissioners  
Meeting with Kingston voluntary organisations  
Meeting with MHA  
Meeting with Plymouth City Council Directors of Social Care and Lead Cabinet members  
Meeting with SCOPE  
Meeting with Shaping Our Lives and National Care Association  
Meeting with Social Workers (National Care Forum AGM)  
Meeting with William Laing  
Members of the care and support alliance - voluntary organisations  
Merseyside Employer Led Partnership Leads meeting  
Ministerial Advisory Group on Mental Health meeting  
NAAPS meeting – micro providers  
NAIDEX conference/exhibition  
National Council for Palliative Care 'Big Conversation'  
National Council for Palliative Care's Older People's Group meeting  
National Homecare Conference meeting  
National Valuing Families meeting  
National Clinical Assessment Service (NCAS) meeting – commissioning for micro-enterprise and provider diversity  
National Clinical Assessment Service (NCAS) meetings with directors of adult services  
National Care Forum AGM

North West Association of Directors of Adult Social Services (ADASS) – Learning to care meeting  
Parkinson's UK conference  
Peers engagement event  
Poole Council consultation event  
Radar workshop  
Radar workshop – disabled people and organisations  
Radar workshop (disabled people)  
Reablement and Hospital Discharge Team meeting in Brent  
Regional Voices – NHS Future Forum and Social Care Engagement meeting  
Role of Co-operatives conference  
Roundtable with Commissioners (LA and NHS), providers, 3rd sector  
Roundtable with Maria Miller  
Standing Commission on Carers (SCOC) meeting  
Seldom Heard Groups – meeting with mental health service users from African & Caribbean backgrounds  
Seldom Heard Groups – meeting with carers  
Seldom Heard Groups – meeting with older adults in residential care  
Seldom Heard Groups – meeting with Pakistani Muslim women  
Seldom Heard Groups – meeting with people from refugee communities  
Seldom Heard Groups – meeting with people from the customer services committee  
Seldom Heard Groups – meeting with people with learning disabilities and autistic spectrum disorders  
Seldom Heard Groups – meeting with young carers (TLAP Future Care report)  
Seldom Heard Groups – meeting with young people with learning disabilities  
Skills for Care Consultation meeting with ADASS-NW/Learning to Care meeting  
Skills for Care Humberside Local Area Network meeting  
Skills for Care Learn to Care meeting  
Skills for Care London Area Network meeting  
Skills for Care meeting with service users  
Skills for Care – Essex, Southend and Thurrock sub-area committee  
Skills for Care – SECHA (Southend Social Care Employer Care Association)  
Skills for Care – Thurrock PVI workshop  
Skills for Care meeting  
Social Care Advisory Group (SCAG) meeting with The National End of Life Care Programme (NEoLCP)  
Social Care for Stroke – Life after the stroke grant for local authorities workshop  
Social Work Reform Board meeting  
South Gloucestershire Council event  
South Yorkshire Local Area Network meeting  
Third Sector Sounding Board meeting  
Think Local Act Personal (TLAP) National Co-production Advisory Group and the Personal Health Budgets forum  
Trafford Dignity in care forum  
UK Advisory Forum on Ageing (UKAFA) conference  
United Kingdom Homecare Association (UKHCA) conference  
United Kingdom Homecare Association (UKHCA) policy forum meeting  
Voluntary Organisations Disability Group (VODG) meeting  
Voluntary Organisations Disability Group (VODG) Operations Directors Network meeting  
Warrington Social Care Partnership  
Wellbeing and Health Open forum  
WRVS – Shaping our age meeting

## **Individuals**

A number of individuals also submitted responses to the engagement. These individuals included service users, carers, relatives of service users, health and social care workers, volunteers and council employees.



## Reference group discussion leads and members

### Quality

**Lead: Imelda Redmond**, Chief Executive, Carers UK

**Members:**

Sharon Allen – Chief Executive Officer, Skills for Care

Cynthia Bower – Chief Executive Officer, Care Quality Commission

Mark Goldring – Chief Executive Officer, Mencap

Martin Green – Chief Executive Officer, English Community Care Association

Sir Andrew Dillon – Chief Executive Officer, National Institute for Health and Clinical Excellence (NICE)

Professor Julienne Meyer – Professor of Nursing, Care for Older Adults, City University London

Julie Jones – CBE Chief Executive, Social Care Institute for Excellence

### Personalisation of care

**Lead: Jeremy Hughes**, Chief Executive, Alzheimer's Society

**Members:**

Sian Lockwood – Chief Executive, Community Catalysts

Julia Winter – Service User

Zandria Pauncefort – Chief Executive, Institute for Citizenship

Miranda Wixon – Managing Director, Home Care Partnership

Martin Routledge – Programme Manager, Think Local Act Personal

Helena Herklots – Services Director, Age UK

Bridget Warr – Chief Executive, United Kingdom Homecare Association Limited (UKHCA)

### Integration

**Leads: Geoff Alltimes**, Chief Executive of Hammersmith and Fulham Council and **Dr Robert Varnam**, GP

**Members:**

Lord Victor Adebawale – Chief Executive, Turning Point

Helen Joy – Policy Leader Chief Executive, Brunel Care

Stephen Bubb – Chief Executive, Association of Chief Executives of Voluntary Organisations (ACEVO)

Sheila Bremner – Chief Executive, Mid Essex Primary Care Trust

Jane Cummings – Chief Nurse and Deputy Chief Executive, NHS Northwest

Lisa Christensen – Director of Children's Services, Norfolk County Council

Tom Hughes-Hallet – Chief Executive, Marie Curie Cancer Care

Dr Niti Pall – Chair and Clinical Lead GP, West Midlands

Councillor David Rogers – Chair of the community wellbeing board at the Local Government Association (LGA)

Dame Philippa Russell – Chair of SCOC, Standing Commission on Carers

Jason Stamp – Chair of Hull LINKs (Local Involvement Networks)

Prof Terence Stephenson – President, Royal College of Paediatrics and Child Health

Peter Hay – President The Association of Directors of Adult Social services (ADASS)

Dr Dermot O'Riordan – Medical Director and Consultant Surgeon, West Suffolk Hospital

## Prevention and early intervention

**Lead:** Alex Fox, CEO, SharedLivesPlus

**Members:**

Sue Adams – Director, Care and Repair England

Michelle Mitchell – Charity Director, Age UK

Julia Skelton – Director of Professional Operations, College of Occupational Therapists

Dr Andrew McCulloch - Chief Executive, Mental Health Foundation

Angela Geer – Director for Older People’s Services, Women’s Royal Voluntary Service

Professor Ann Netten – Director of PSSRU, University of Kent

## Diverse and responsive care market

**Lead:** Peter Hay, Strategic Director, Adults and Communities for Birmingham City Council and President of the Association of Directors of Adult Social Services

**Members:**

Prof Andrew Kerslake – Director of Institute of Public Care, Oxford Brookes University

Des Kelly – Executive Director, National Care Forum

Bridget Warr – Chief Executive, United Kingdom Homecare Association Limited(UKHCA)

George McFarlane – Confederation of British Industry (CBI)

Marije Davidson – Public Affairs Manager, Royal Association for Disability Rights (RADAR)

## The role of financial services

**Lead:** Nick Kirwan, Assistant Director of Health and Protection, Association of British Insurers:

**Members:**

Gordon Morris – Managing Director of Commercial Services, Age UK Enterprises

Dr Ros Altmann – Director General, SAGA

Baroness Sally Greengross – House of Lords

David Brown – Partner at Price Waterhouse Cooper