Achieving age equality in health and social care

A report to the Secretary of State for Health by Sir Ian Carruthers OBE and Jan Ormondroyd

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Letter to the Secretary of State for Health

Dear Secretary of State for Health,

Following the invitation to undertake this review of age equality in health and social care in England, we have been working with a wide range of experts, stakeholders, staff and members of the public to develop our recommendations. While ending age discrimination and advancing age equality may not appear to some to be at the heart of the agenda for the NHS and social care, over the six months of the review there has been media coverage of the discussion about the cancer survival rates of people over 75 in the UK, whether the age bands in the cervical screening programme should be revised and how as a society we should fund the care of older people. The increasing aspirations of society combined with the changes in the age profile of the population mean that differences in the care and treatment between age groups will be under great scrutiny in the coming years. Society, service users and their carers will ask whether these differences are fair and meet the needs of people at different stages of life.

The evidence is clear that there has been progress in addressing age discrimination in the health and social care system in recent years. We need greater consistency across all locations and all services covering both young and old to tackle what some people call “hidden” or “covert” age discrimination. Greater transparency will be essential to making this improvement happen.

Although many people have told us about the excellent care they have received, we have also heard of inappropriate things said, especially to older people – this was neatly summed up in the phrase “what do you expect at your age?” Although often not intended, there is no doubt about the impact of such words on the experience of patients, service users and their carers. People expect to be treated fairly and with dignity at all ages and not judged by their age. This applies just as strongly to younger people as to older people and to carers as much as to patients and service users themselves.

We have looked at services that are targeted at people of specific ages, such as the screening and vaccination services. For most there is a body of evidence supporting

the age criteria. This needs to be reviewed regularly to reflect scientific progress. Although most services do not exclude people simply because of their age, we have seen data that shows marked differences in service provision between age groups that are hard to explain by reference to the patterns of need. We have heard about care assessments and decisions whether to refer for investigation or treatment where it has been assumed that because of their age, the patient or service user will not want or will not benefit from a specific treatment or a care package.

Our conclusion is that the new Equality Bill provides an unprecedented opportunity for the health and social care system to build on the progress already made, truly eliminate age discrimination and take further strides in ensuring care is personal and meets the needs of each individual and their carers regardless of age. The law can be effective in highlighting the need for action, but ending age discrimination and promoting age equality are as much about changing the attitudes and behaviours of individuals and the culture and practices of organisations. The evidence presented to us has been that staff rarely set out to be ageist but that for a range of reasons, their actions sometimes did not meet the needs of the patient or service user who was in front of them. This can be seen as simply poor service quality, though it is clear that some age groups, especially older people, are much more likely to receive poor services. Importantly it means that the solutions to ending age discrimination and promoting age equality are not, in general, a range of new policy initiatives from government but are the more effective design and implementation of existing policies and changes in the provision of services, especially the focus on the needs of the individual person set out in *High Quality Care for All* and *Putting People First.*

It is for this reason that we are recommending that the health and social care system should implement the ban in the Equality Bill on age discrimination, harassment and victimisation at the same time as it comes into force for other sectors. The current thinking of the Government suggests that this should be in 2012 and the NHS and Local Authorities should work to the same timetable to which other sectors have already committed. The health and social care sector should be at the leading edge of ending age discrimination and promoting age equality – fairness in ensuring that services are provided on the basis of people's needs, personalised to them as individuals, is at the core of the NHS and social care. We asked care and health professionals and managers if there are any good reasons why their services should implement the Bill later than other parts of the economy. Clearly, the financial context in the coming years will be particularly challenging, but the evidence we have considered strongly suggests that as long as there is reasonable notice, staff want to finish the task that they started through the National Service Framework for Older People and the transformation programme in adult social care.

This ambition is rooted in the underlying values of the health and social care system, and leads us to be confident that there is a firm basis for making real and rapid progress towards a system that tackles existing age discrimination and, just as importantly, creates an environment that prevents future age discrimination and enhances equality of opportunity.

The level and the quality of engagement from the public, NHS and social care organisations and a wide range of stakeholders has been very positive. The rich variety of responses to our call for evidence and the spirited and insightful contributions of the many leaders and members of stakeholder organisations we met in the course of conducting the review demonstrated to us that, while views about priorities and some of the detail may vary, there is a strong and widespread commitment to ensuring that the NHS and social care are able to provide high quality care to all people, whatever their age.

Our work would not have been possible without the input of John Dixon, Director of Adult and Children's Services at West Sussex County Council who chaired the National Advisory Group, and shared his insights and wisdom with the review team. We also thank everyone who has contributed to our work especially the members of the National Advisory Group, national organisations, colleagues and members of the public. The South West in particular has played an important role in the process and we would like to thank the staff of statutory organisations and third and independent sector providers and members of local groups, especially the older people's forums across the South West who have been an invaluable source of validation and challenge for our analysis. Alongside the review, we are producing a resource pack to help the Local Authorities and the NHS to work with local people in ending age discrimination in each area. We have commissioned an analytical tool and good practice guidance that we recommend are tested and refined with input from around the country. We would particularly like to thank those who have developed these products, especially those in the Local Authorities and NHS in Bristol, Cornwall and Dorset.

We hope that this review provides a clear and powerful stimulus to secure further service improvement. We were asked to provide recommendations on the implementation of the Equality Bill. In addition, we are issuing a challenge to the Department of Health and the various national bodies that oversee the health and social care system, to individual NHS organisations and Local Authorities, to the third and independent sectors and to members of staff and the teams in which they work to complete the work they have started and take the next steps on the journey to both end age discrimination and to work towards greater equality for people of all ages. Fundamentally, this is about treating people as individuals through greater personalisation and improving the quality of life for everyone. This will be achieved by ensuring the services available to all who use them and their carers meet their individual needs in the most personal way in order that standards of care and quality of life improve for everyone.

Yours Sincerely

Sir Ian Carruthers OBE
Chief Executive
NHS South West

Jan Ormondroyd
Chief Executive
Bristol City Council

Achieving Age Equality in Health and Social Care: Summary

1. In April 2009, the Secretary of State for Health asked Sir Ian Carruthers OBE (Chief Executive of NHS South West) and Jan Ormondroyd (Chief Executive of Bristol City Council) to undertake a review of age discrimination and age equality in the health and social care sector.

2. The health and social care review supports implementation of the age provisions of the Equality Bill that is currently before Parliament, which:

   - bans age discrimination against adults in the provision of services and exercise of public functions; and

   - creates a public sector duty to have due regard to the need to the need to eliminate discrimination and to advance equality of opportunity and foster good relations between people who share a protected characteristic and people who do not share it. The duty applies to eight protected characteristics, one of which is age. The ban on age discrimination applies in relation to adults (people aged 18 or over), but the public sector duty applies in relation to people of all ages, including children.

3. The review was asked to produce recommendations on the timing of implementation for the age discrimination ban in health and social care, and on any exceptions to the ban that might be necessary. It was also asked to recommend the key actions that the health and social care system should take to make demonstrable progress in meeting their obligations as quickly as possible.

4. The review took account of the wider context of change in social care and health. In particular, it considered age discrimination and age equality in the context of personalisation. Matching services more closely to the needs, preferences and aspirations of service users and carers is essential both to delivering greater personalisation *and* to tackling age discrimination. The financial challenges that health and social care services are going to face in the coming years provided a second, crucially important context for this review. It is clear that, in a future with tighter funding than in recent times, service redesign to free up resources to provide better, more equitable care and a stronger matching of resource and need through personalisation and, in some situations, redistribution of resource will be the principal means by which organisations responsible for funding care will implement this agenda.

5. The review has looked at all parts of the health and social system. National organisations shape the strategic direction. Local commissioners in primary care trusts and local authorities identify local needs and design services, working in partnership with local people. Local social and health

care services are part of a wider network of services that contribute to the well-being of the local population so we have looked at the links with, for example, housing, leisure and benefits. Providers of care in the statutory, independent and third sectors deliver services to people in a number of different settings such as residential and hospital care and community-based and home-centred care.

6. The review analysed evidence of the nature, extent and variability of age discrimination in the health and social care system. It also considered what is already in place in the system to tackle age discrimination and support greater age equality. It looked at evidence from a wide variety of sources, including academic research, stakeholder submissions, personal testimony and the conclusions of a number of workshops and engagement events.

7. The review has focused on practical solutions that connect with the language, experience and processes of NHS and social care organisations – and the people who use health and social care services.

8. The review has come to a number of key conclusions and recommendations:

- Despite recent progress, and the good service received by many people of all ages, age discrimination remains an issue for the health and social care system which all organisations need to address.

- Many of the examples of age discrimination that have been shared with us are of indirect discrimination but these have just as detrimental an impact on patients, service users and carers and on public confidence in the system as direct discrimination.

- Pressing ahead with a number of existing commitments (including the personalisation agenda, *High Quality Care for All* and *Putting People First*), will do a great deal to advance age equality and tackle discrimination.

- A specific focus on age at local level is required: local audit and planning processes should include an age dimension, and clear action to advance age equality and tackle discrimination needs to be identified and followed through locally. A number of resources have been developed alongside the review to support local organisations to make rapid, substantial and demonstrable progress.

- The ban on age discrimination should come into force for health and social care at the same time as for other sectors. Current Government thinking is that this is 2012.

- Health and social care services, or parts of them, should not be removed wholesale from the scope of the ban on age discrimination. In principle, there could be a case for spelling out in more detail in the legislation

particular tests services need to meet if they are to be lawful (i.e. creating 'specific exceptions'), but the review has not identified a specific need for such provisions.

- Negative attitudes and narrow assumptions about age but particularly about older people, are an important cause of age discrimination. Action to shape attitudes through training and professional standards is therefore critical.

- Discriminatory behaviour is often bound up with other factors contributing to poor quality care: leaders within the system need to take responsibility for tackling age discrimination as part of achieving high quality care.

- The organisations and individuals responsible for distribution of resources within the system will need to ensure that their practice conforms to the new legislative requirements, and in some situations this will mean a redistribution of resources so that needs are met more fairly.

9. Following publication of the review, we recommend that the Government develops and consults upon its response to the recommendations. This should be done in parallel with the further development of the resource pack in the South West working with health and social care organisations from other regions.

Summary of conclusions and recommendations

The conclusions and recommendations are set out in the main body of the report but are presented here, grouped for national organisations, the whole sector and for local organisations.

Recommendations for national organisations

We recommend that:

p.18 The Department of Health consults formally on the action it proposes to take in the light of this report. [Recommendation 1]

p.27 The Department of Health ensures that a programme of research is commissioned that enables the Advisory Committee on Breast Screening to advise on the upper limit of the breast cancer screening programme, and regularly updates the evidence. [Recommendation 3]

p.29 Subject to the outcome of the consultation process on the age provisions in the Equality Bill undertaken by the Government Equalities Office, the Government should set the same commencement date for the ban on age discrimination in health and social care as in other sectors [currently envisaged to be 2012]. [Recommendation 5]

p.30 There are no areas within health and social care that should be removed wholesale from the scope of the ban on age discrimination. [Recommendation 6]

p.31 The Government should consider further whether any more specific exceptions are needed for health and social care. We do not think there is anything wrong in principle with such exceptions, but we have not identified a compelling need for any. [Recommendation 7]

p.31 The Department of Health should set out how it and the Advisory Committees and Executive Agencies that it sponsors will ensure public confidence by assessing age-based criteria in a transparent manner, leading to changes in policy if required. Arms-length Bodies, such as Executive Non-departmental Public Bodies, should satisfy themselves that any age-based criteria they apply comply with the new legislation. [Recommendation 8]

p.33 *The Department of Health should review the relative weighting of the two Relative Need Formulae (RNF) for adult social care before 2012. It should also ensure that this and future reviews of the formulae ensure compliance with the ban on age discrimination and the public sector equality duty.*

[Recommendation 9]

p.34 *The Department of Health formally asks the Advisory Committee on Resource Allocation (ACRA), to ensure that its future recommendations comply with the age discrimination ban and the public sector equality duty in its ongoing work.* *[Recommendation 10]*

p.35 *The Department of Health and the NHS review the use they make of quality-adjusted life-years (QALYs) and other similar support tools to inform their decision-making prior to the Equality Bill coming into force.*

[Recommendation 11]

p.37 *The Department of Health should ensure there are clear and emphatic references to ending discrimination in relation to the eight protected characteristics (including age) and advancing equality in the 2010/11 World Class Commissioning assurance process.*

[Recommendation 12]

p.41 *All professional regulatory organisations will need to review and, if necessary, revise their standards, codes of conduct and education programmes to advance equality and to ensure that age discriminatory behaviour is clearly identified as unacceptable and a failure in professional standards.* *[Recommendation 14]*

p.49 *The Department of Health should work with the Health and Social Care Information Centre to explore how to construct an age-specific dataset to support the resource pack and help local organisations analyse and monitor patterns of service provision by age. This must link into wider work on indicators, including the programmes of the Public Health Observatories and the National Indicator Set.*

[Recommendation 24]

p.49 *Future performance measures that are both proportionate and targeted should be developed in accordance with the age discrimination ban and the public sector equality duty.* *[Recommendation 25]*

p.49 *All relevant national regulatory organisations, especially the Equality and Human Rights Commission and the Care Quality Commission, should work together and with the Department of Health to ensure that a shared understanding of the implications of the law is the basis for registration, inspection, regulation and assessment of the health and social care system.* *[Recommendation 26]*

p.50 *The Department of Health should ensure that an up-to-date pack of resources, including good practice material, is available to health and social care organisations to support them to meet the requirements of the Equality Bill relating to age, and consider whether to identify national centres of expertise to co-ordinate work at a regional level to implement the provisions of the Equality Bill.* *[Recommendation 27]*

p.51 *The Department of Health through the NHS National Institute for Health Research and its school for social care research should review the relevant guidance to ensure it is compliant with the Equality Bill, and promote further research on ageing.* *[Recommendation 28]*

Recommendations for both national and local organisations working in the health and social care sector

We recommend that:

p.42 *All organisations responsible for education and training in health and social care will need to ensure that their curricula and programmes enable staff and trainees to apply the law effectively in time for its commencement. We recommend that the providers of education develop ways of involving older people in the delivery of education programmes, especially to trainees at an early stage in their learning.* *[Recommendation 15]*

p.47 *The Department and the health and social care system ensure that work to prevent harm and waste and spread innovation within the system should be designed to help promote age equality and that measures to end age discrimination are implemented so that they improve quality and productivity.* *[Recommendation 20]*

p.48 *The Department of Health and the wider system ensure the use of tools such as Equality Impact Assessments to ensure compliance with the age discrimination ban and the public sector equality duty in all new policies.* *[Recommendation 21]*

p.48 *The Department of Health develops a joint assurance process for social care and health to demonstrate progress with implementing the age equality provisions of the Equality Bill. The Equality and Diversity Council should consider how to support this process to ensure it is aligned with other assurance processes covering health and social care.* *[Recommendation 22]*

Recommendations for local organisations

We recommend that:

p.25 Every provider and commissioner of mental health services will need to consider how to achieve non-discriminatory, age-appropriate services, drawing on insights from reports such as Equality in Later Life and other sources of good practice. [Recommendation 2]

p.27 Health and social care organisations work in partnership to implement demonstrated best practice in prevention programmes that improve the quality of life of older people. [Recommendation 4]

p.38 Local Authorities review their assessment procedures and the resulting packages of care and funding arrangements for both service users and carers in preparation for the new legislation focusing on the outcomes that are delivered for service users and their carers. [Recommendation 13]

p.42 Local statutory organisations should build into their contracts with providers of training programmes (including, third sector and private organisations) the need for an explicit focus on age equality that supports staff in providing high quality services to people of all ages. [Recommendation 16]

p.42 Leaders of health and social care organisations, including the boards of those organisations and Elected Members, will want to set out a clear commitment to their staff and the wider public to meeting the requirements of the age discrimination ban and the public sector equality duty and demonstrate how the health and social care sector can show leadership in tackling ageism in society. [Recommendation 17]

p.44 Local NHS and social care organisations consider how they can use the new NHS and social care complaints process to achieve rapid resolution of individual instances of potential discrimination. [Recommendation 18]

p.46 Local social care and health commissioners and providers will want to work together to implement the age provisions in the Equality Bill. We are producing a resource pack to support local communities and recommend that the local approaches share the following features/ outcomes:

- *Led by Primary Care Trusts (PCTs) and Local Authorities (LAs), with joint audit of services, systems and processes across health and social care;*

- *Joint action planning across health and social care that sets out how local organisations will meet the public sector equality duty and comply with the age discrimination ban;*

- *Work with NHS, LA, third and independent sector providers and those working in them to embed actions in provider improvement plans;*

- *Assessment and agreement of the local resource consequences of implementation within local funding parameters;*

- *Involvement of members of the public in the work through Local Involvement Networks (LINks), forums and other networks and discussion of the conclusions of the local analysis by NHS Boards and Elected Members in public;*

- *Use the local scrutiny processes and bodies such as Health Overview and Scrutiny Committees to provide transparency and build public confidence;*

- *Build on existing approaches to implementing equalities and quality improvement but recognise that the age provisions in the Bill are a new requirement.* *[Recommendation 19]*

p.49 *Local Authorities use the Joint Improvement Partnership process to share learning and progress, thus ensuring linkage with the implementation of Putting People First.* *[Recommendation 23]*

Introduction and context

1.1 In April this year, the Secretary of State for Health asked us to conduct a review of age discrimination in health and social care services to inform a number of Ministerial decisions related to implementation of the Equality Bill currently making its way through Parliament. We were also asked to advise Local Authorities and the NHS on how to prepare to implement the legislation once it is passed. This report sets out our findings and recommendations. The system[1] has made good progress in tackling age discrimination in recent years. Our work has supported the conclusion of the three regulators in 2006 – much explicit age discrimination has been addressed following work to implement the National Service Framework (NSF) for Older People and the Fair Access to Care Services Guidance[2]. For some people, however, their age can still have a negative impact on the level or quality of service they receive. Most, though not all, of the discrimination that persists tends to be less explicit and is often linked to ageist attitudes and assumptions and the decisions and behaviour that flow from them both in the care of individuals and in the priorities of the wider system. The majority of the evidence that we have received suggests that age discrimination mainly disadvantages older people, but there are also some examples of younger and middle-aged adults experiencing unfairness.

1.2 The new legislation reinforces a number of features and developments of the system already in place:

- the **values** held by the system and the people within it;
- the **strategic direction** of the system as manifested in the implementation of key policies in health and social care;
- recent **progress in tackling age discrimination**; and
- **demographic trends** in our society and the changing attitudes and aspirations of people at different ages.

1.3 The following sections consider these contexts in more detail, along with the new legislative context.

1 References to 'the system' throughout this report should be read as references to both health and social care.

2 *Living well in later life: A review of progress against the National Service Framework for Older People,* The Healthcare Commission, the Commission for Social Care Inspection and the Audit Commission, March 2006.

Values

1.4 The National Health Service and the social care system are rooted in the idea of fairness. This is an idea in tune with the basic values of the millions of people who work in health and social care organisations – and with wider society. While there will always be disagreement about the fairness of particular decisions, there is clear evidence of a strong and widespread commitment to make the idea of fairness a reality for the people the system serves. The recently published NHS Constitution, the product of widespread consultation, captures the commitment to fairness at a number of points including the first of the NHS Principles which states 'The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion or belief'[3]. *Putting People First* sets out a complementary set of values for social care[4].

Strategic direction

1.5 Recent key policies and strategic developments also positively reinforce work to address age discrimination and advance age equality:

- The increasing focus on **personalisation** in both social care and health. This is a central theme of both *Putting People First* and *High Quality Care for All,* and was also a key theme of the recent Green Paper *Shaping the future of care together*[5]. Systematic implementation of personalisation across the country (including appropriate support for individuals of all ages) will do a great deal to promote age equality. It empowers people in making choices about their care and treatment and (though there are times when people do not want to be faced by a panoply of options) patients and service users of all ages want their views to be heard and their preferences respected.

- Linked to personalisation, work to **improve the quality of care provided to people of all ages.** This will be done through both **strengthening commissioning and supporting providers in their quality improvement programmes**. The focus must be on health and well-being outcomes and on the experience of patients and service users.

3 NHS Constitution, January 2009, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093419. See also the rights section of the Constitution, which includes the 'right not to be unlawfully discriminated against in the provision of NHS services including on grounds of …age', and the right 'to be treated with dignity and respect, in accordance with your human rights'. Furthermore, the responsibilities section of the Constitution (for NHS staff) includes a 'duty not to discriminate against patients or staff' and the Values section includes 'Everyone counts. We use our resources for the benefit of the whole community, and make sure nobody is excluded or left behind'.

4 *Putting People First,* DH, 2007- http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf.

5 *High quality care for all: NHS Next Stage Review final report,* Professor the Lord Darzi of Denham KBE, June 2008, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825. For *Shaping the future of care together*, DH 2009, see http://careandsupport.direct.gov.uk/

- Finally, the health and social care system in the **new and challenging financial climate** will need to focus strongly on getting the most out of its resources. Care that is non-discriminatory is, by definition, a better match of need with resource, and so we can see alignment between the equality agenda and work to meet the challenge of the financial climate in the coming years. The recent progress in addressing age discrimination has been achieved during a time when the NHS has experienced substantial increases in funding. In the near future both the health and social care systems will face a very different funding position and so it is imperative that the improvements in age equality are consolidated. Further progress is part of reducing waste and unjustifiable variations in care and spreading innovation and excellence. New approaches to ending age discrimination provide opportunities to improve productivity by preventing the costs that result from harm and illness, and promoting the savings that result from good health and well-being.

A large part of the work to address age discrimination can be achieved simply through the system delivering the ambitious changes to which it is already committed. Advancing these strategic aims will also be an important contribution to achieving the public sector equality duty set out in the Equality Bill.

1.6 Examples of discrimination can often be indications of wider failures to deliver strategic intentions. Work to investigate, tackle and prevent age discrimination will therefore form part of the wider quality improvement process to which staff and organisations are already strongly committed.

Progress in tackling age discrimination

1.7 There is clear evidence that the NHS and Local Authorities have made progress in addressing some aspects of age discrimination in recent years. There is also clear evidence that discrimination remains, but the work to challenge attitudes and to eradicate explicit age discrimination has demonstrated the capacity of the system to address problems, and provides a platform for further work[6]. The next phase of improvement will need to focus on the less explicit discrimination that the review has found in health and social care. Many health and social care organisations have used Single Equality Schemes to implement measures to improve equality and they have often included age within these schemes, though usually in less detail than the other 'protected characteristics'.

6 See *Living well in later life.*

The changing legal context

1.8 The Equality Bill sets out a clear legal requirement to treat adults of all ages in a non-discriminatory manner when providing services, and bans both direct and indirect discrimination on the basis of age[7].

1.9 The changes in the law set out in the Equality Bill that is currently progressing through Parliament, including a ban on age discrimination in the provision of services and the exercise of public functions and a new public sector equality duty, provide an important catalyst for change.

1.10 The ban on age discrimination will make it unlawful to treat someone less favourably because of their age (direct discrimination) or because of a provision, criterion or practice that puts them and others of their age group at a particular disadvantage because of their age (indirect discrimination). Where less favourable treatment because of age is shown, in the words of the legislation, to be a 'proportionate means of achieving a legitimate aim', it is not direct or indirect age discrimination[8]. The Equality Bill also includes provision to specify exceptions to the ban on age discrimination.

1.11 The new public sector equality duty will require all who carry out public functions to have due regard to the need to:

- eliminate discrimination
- advance equality of opportunity and
- foster good relations

across the relevant 'protected characteristics', including age.

1.12 The new duty offers the NHS and local authorities a valuable opportunity for addressing multiple discrimination, as our local engagement work has shown. Efforts to tackle multiple discrimination will be further supported by the provisions in the Bill on discrimination because of a combination of two protected characteristics, and by the Government's drive to tackle other factors, such as rural isolation or socio-economic disadvantage.

1.13 Although the ban on age discrimination applies to adults over 18, we have also considered issues relating to adults of all ages, including the transition from child orientated to adult services. The duty to promote equality applies to all ages, including children.

7 The Equality Bill, April and July 2009, http://services.parliament.uk/bills/2008-09/equality.html

8 The term 'proportionate means of achieving a legitimate aim' is often phrased in less formal terms as 'objective justification', and we follow this usage in the review.

Demographic trends

1.14 It is well known that the age profile of our population is changing, and our society recently reached the significant milestone of having more pensioners than people under 16[9]. As this trend continues, health and social care services will serve a larger proportion of users from the older age groups than ever before. Age discrimination and the challenge of advancing age equality is not confined to older people (a fact recognised by the Equality Bill): for example, the recent National Dementia Strategy *Living well with dementia* covered all age groups, and local systems will need to ensure that appropriate services are in place to meet the needs of younger people with dementia as well as older people[10]. Nevertheless, the majority of the examples that have been presented to us have been examples of discrimination experienced by older people.This means that the changes in the structure of the population and consequent changes in the structure of need are an important context for tackling age discrimination and ensuring age equality now and in the future[11].

1.15 In addition, research has identified a parallel trend for current and future generations of older people to expect and demand more from services[12]. A desire for services to respond to their views and to be designed with the needs but also the preferences of users is emerging more strongly, and replacing some of the more passive behaviour of earlier generations. We recognise this but our local engagement work has also highlighted that people of all ages, but especially older people, can sometimes feel overwhelmed by having choices presented to them with little or no advice. This leads to the conclusion that supporting decision-making must be a central part of the implementation of personalisation.

Conclusion

1.16 The system's recent progress, its basic values, the increasingly supportive context of the wider system, the new legal imperatives and the demographic and attitudinal changes that new generations of older people are bringing to

9 *Building a society for all ages,* July 2009, http://www.hmg.gov.uk/buildingasocietyforallages/download.aspx, p5

10 *Living well with dementia,* DH, 2009- http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058

11 One of the key changes in need is the rise in long-term conditions. Around 15.4 million people in England currently have a long-term condition (including three out of every five of the over-60s) and the number is expected to rise by 23% over the next 25 years- 'Ten things you need to know about long-term conditions', DH, http://www.dh.gov.uk/en/Healthcare/Longtermconditions/tenthingsyouneedtoknow/index.htm.

12 'There are now 17 million baby boomers marching towards retirement with a high set of demands and a clear expectation of what they want in retirement. They are a diverse group: containing amongst the richest and poorest people in society, with great differences in values, life experiences and expectations. But despite their diversity, this research highlights that the opinion of the baby boomers unites around key areas of concerns. They want to see improvements in the NHS, pensions, care, levels of crime and public services', Age Concern, *Looking Beyond the Grey* 2004

bear on the system add up to a case for early action to tackle age discrimination and advance equality of opportunity between age groups. The rest of this review sets out recommendations for action and the evidence and analysis behind them.

1.17 ***We recommend that the Department of Health consults formally on the action it proposes to take in the light of this report.***
[Recommendation 1]

Task and method

2.1 Before setting out the evidence we gathered and the conclusions it has led us to, this chapter describes the scope and focus of the review, and the ways in which we gathered evidence of different kinds.

2.2 Our approach has been informed by the four principles of change set out by the NHS Chief Executive in November 2008 –

- co-production,
- subsidiarity,
- local leadership, and
- system alignment.

This led us to look at how advancing age equality can be built into local quality improvement agendas.

Terms of Reference

2.3 The objectives set for the review by the Secretary of State were as follows:

- To recommend the timetable by which health and adult social care organisations will implement the ending of unjustifiable age discriminatory practice in the provision of services as set out in the Equality Bill;
- To recommend for which health and adult social care services it is beneficial and therefore objectively justifiable to retain age-based differentiation;
- To advise the Secretary of State on how to support the health and social care system to implement the public sector equality duty in respect of all ages;
- To recommend the key actions that the health and social care system should take to make demonstrable progress in meeting their obligations as quickly as possible.

2.4 The review was also asked to take into account the 'financial and planning framework' for the health and social care system in the coming years.

Method and approach

2.5 The approach we have adopted in this review has been characterised by a **local focus**, allowing us to see the issues from the perspective of service users and service providers, and a **broad thematic analysis** of the causes and character of age discrimination. This combination of local depth and thematic breadth has been brought together in the development of a resource pack for the NHS and LAs, which seeks to cover the wide range of issues pertinent to age discrimination in a form that is resonant and useful for local services. Annex A describes the approach in more detail.

Local focus

2.6 The review was set up as a national review rooted in the experience of the health and social care system in the South West and this has been a helpful approach for developing recommendations that are credible in terms of local and regional delivery as well as ensuring a focus on the practical steps that can be taken. This has led to a positive emphasis on identifying what good, age-equal care looks like and on what is required in terms of capacity to assess, measure and deliver this locally.

Breadth of analysis

2.7 A number of literature reviews have demonstrated that there is no single measure or indicator to prove age discrimination, or for age equality.[13] Simply comparing the use of resources between age-groups is an insufficiently precise measure, because it does not take into account differences in need or in capacity to benefit from interventions that can occur between age groups – though differences in resource use can be important pieces of evidence when taken together with other evidence. Similarly, differences in outcomes (including both clinical or functional outcomes and user experience) can also tell us something as part of a wider picture, but cannot be relied upon in themselves (for example, older people tend to rate services more highly than younger people, but this may reflect entrenched cultural attitudes rather than 'real' differences of experience and quality). Looking at the processes followed by organisations (particularly in relation to the commissioning of services) to identify the needs of different age groups and to ensure that the voices of those age groups are heard can also tell us something – but again not everything – about how well an organisation is doing in addressing age discrimination.

13 Four reviews were commissioned by the Department of Health from the Centre for Policy and Ageing: Ageism and age discrimination in primary health care in the United Kingdom (April 2009), Ageism and age discrimination in secondary health care in the United Kingdom (April 2009), Ageism and age discrimination in mental health care in the United Kingdom (forthcoming), and Ageism and age discrimination in social care in the United Kingdom (forthcoming)

2.8 This review has therefore looked at age discrimination from a number of different perspectives, ranging from system-wide issues such as resource allocation, through the practices and policies of organisations working together in a locality to the attitudes and behaviour of individual practitioners and their teams when they interact with patients, service users and their carers. It has drawn on 'hard' evidence, such as analyses of statistics and funding formulae, and the 'softer' evidence of personal testimony and opinion[14].

14 For a good example of this kind of evidence, see *Worth Fighting For: Ten Stories of Ageism,* Help the Aged 2009.

Defining the Problem: what people told us and service-level issues

3.1 The call for evidence, local discussions and the meetings held with individual stakeholder organisations provided a rich and varied range of evidence for this review. We have drawn extensively from this material for our analysis and recommendations and, in this chapter, we briefly set out an indication of the level and variety of the responses we received.

3.2 Addressing age discrimination requires a focus on specific services and we have adopted a "pathway" approach, looking at the journeys that patients, service users and carers often experience across health and social care boundaries. The resource pack that we have commissioned will help the NHS and Local Authorities review their local services, looking at all ages but focusing on the sectors where the evidence highlights the greatest challenges. We have highlighted three specific areas in this chapter while later chapters of this review highlight cross-cutting issues that apply to all or most services.

What people told us: messages from the call for evidence and stakeholder engagement

3.3 The review process highlighted important evidence across the spectrum of questions raised by our terms of reference. Responses to the call for evidence provided detail on existing age differentiation in health and social care systems, services and resource allocation processes. We also learned a great deal (particularly through meetings with key stakeholders) about how the culture, behaviour and attitudes of practitioners and organisations can contribute to discrimination. The local engagement events provided an invaluable opportunity to focus on the practical implementation issues.

3.4 A number of stakeholders identified the importance of the new legislation in bringing about a change in culture, and several responses also emphasised the need for implementation to go beyond a focus on legal compliance to build upon existing work and policy direction.

3.5 The timetable for implementation was considered by some of the responses to the call for evidence. The dates proposed ranged between 2010 and 2012, with no submission proposing a date later than 2012. Several responses discussed the need for phased or transitional implementation, and some also stressed the importance of specifying dates for the process of implementation. In the local engagement events we discussed possible reasons for delaying beyond 2012 but there was a consensus that health and social care should not be later than other sectors and that, despite the pressures on resources in the near future, a two-year lead-in time would focus attention but also provide enough time to prepare.

3.6 Many respondents argued that there are a number of areas where different treatment or provision based on age is beneficial. Examples mentioned included screening and vaccination programmes (such as seasonal flu vaccinations and cervical cancer screening), early intervention psychosis services, and specialist older people's psychiatry. Also mentioned were benefits such as free eye tests and prescriptions for older people. Respondents were clear that the use of age ranges and age-differentiated services needed to be grounded in good evidence about at-risk groups, and sensitivity towards the needs of individuals.

3.7 A strong message from the call for evidence and the discussions with stakeholders was the need for 'equality of aspiration' in services provided for older people when compared with those given to younger people. Many respondents called on commissioners and service providers to recognise that older people have aspirations that services can help them to realise – not just clinical or functional needs.

3.8 Other issues included:

- the crucial part played in providing age-equal services by good communication between practitioners and those using services;
- the importance of attitudes, values and behaviours of individuals and organisations;
- the drive to improve quality and productivity through reducing waste and variation, preventing harm and spreading innovation and excellence;
- the overlap between poor quality services and discriminatory services; and
- the importance of personalisation and the need to make sure it works for everybody, including older people.

3.9 Many respondents also gave their perspective on good, non-discriminatory services, identifying the following factors:

- physical access (including transport) especially in rural areas;
- high quality, appropriate information, including the use of accessible formats (which might include large print, audio versions and languages other than English);
- communication and involvement;
- personalisation;
- evidence-based and needs-based decision-making;

- integration of health and social care services;
- application of equal standards for all age groups;
- personalised support at transitions;
- training programmes which deal explicitly with the need to provide age-equal services.

3.10 The evidence also identified a range of actions that would help NHS organisations and Local Authorities implement the equality duty, including joint planning, integrated redesign, workforce development, analysing and addressing gaps in services at the times of life when people transfer between services and monitoring and assessing progress.

Service-level issues

3.11 In this section, we describe some of the evidence of age discrimination in three service areas. PCTs will need to work with their practice based commissioning teams, Foundation and NHS Trusts with their clinical directorates, Local Authorities with their social services teams and other directorates to look across all services to identify potential age discrimination and opportunities for promoting age equality. Here we focus on three services: mental health because the major review carried out in 2006 by the three regulators identified this as an area where there had been less progress; cancer services, because this highlights the ongoing need to review policy and practice in the light of scientific progress; and prevention because it illustrates the benefits that integrated working between health and social care can deliver. All three areas highlight generic issues but also require specific action.

Mental Health

3.12 Many mental health providers have traditionally organised their services into working age and older adult services and this pattern has been reinforced by policy divisions between the Mental Health and Older People National Service Frameworks[15]. The division is not of itself discriminatory – in fact, it could be an example of positive action and support personalisation. We have been given examples of high quality, age-appropriate specialist services focusing on the specific needs of older people. However, the unintended effects of this appear to have been a disparity of service between older and working age adults and a transition from one service to the other that has not

15 *National Service Framework for Mental Health,* DH 1999, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009598; National Service Framework for Older People, DH, 2001, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003066

always met the needs of individuals effectively. The goal must be that services are provided based on need not age.

3.13 *Equality in Later Life*, a report by the Healthcare Commission, examined six mental health trusts and found evidence of ageism in the form of:

- exclusion of older people from mental health services that are available to younger adults;
- very low levels of referrals from GPs to specialist units for older mental health sufferers; and
- a general lack of age appropriateness[16].

However, the report also found that two out of the six trusts examined had made significant progress towards eliminating ageism in their service provision. These two trusts took very different paths in terms of structure but the common feature was the role of clinical and managerial leaders in bringing about change.

3.14 The recently published Department of Health consultation on a strategic direction for mental health, *New Horizons* addresses the issues set out above, and proposes a policy framework that integrates the needs of working age and older people, which this review strongly supports[17]. It also describes an approach to managing the division between working age and older adult mental health services, which appears to offer a helpful way forward. A number of mental health trusts have developed formal agreements between services aimed at different age groups; these agreements are designed to manage the division in a way that is focused on meeting individual needs and preferences. This approach may be of use in other service areas as well.

3.15 While the improvement in the strategic framework for mental health services across all ages is clearly a helpful development, it will not (as the recent report of the Royal College of Psychatrists makes clear) be sufficient in itself[18], and ***every provider and commissioner of mental health services will need to consider how to achieve non-discriminatory, age-appropriate services, drawing on insights from reports such as Equality in Later Life and other sources of good practice.***

[Recommendation 2]

16 *Equality in later life,* Healthcare Commission, 2009

17 *New Horizons,* DH 2009, http://www.dh.gov.uk/en/News/Recentstories/DH_097701

18 *Age Discrimination in mental health services: making equality a reality*, Royal College of Psychiatrists, 2009. Among other issues, this helpful report highlights the need to improve access to specialized services for older people, broadening suicide prevention to all age groups, and improving assessment in primary care, moving away from assumptions that depression is an inevitable feature of old age.

Cancer

3.16 The United Kingdom has a higher death rate from cancer than the rest of Western Europe and the United States in people aged seventy-five years and over, and while there has been progress across all ages in reducing cancer mortality, that progress has been faster among younger people. The Cancer Reform Strategy in 2007 has begun to tackle this by setting out the clear principle that the only acceptable criteria for not giving a clinically appropriate and cost effective treatment should be poor patient health or patient choice[19].

3.17 Flowing from the Cancer Reform Strategy, the National Cancer Equality Initiative (NCEI) has been created to tackle inequality challenges head on. Seventy-seven Primary Care Trust cancer networks are working on inequality issues with 34 focusing specifically on age[20]. The NCEI are considering proposals to pilot frailty scoring for access to cancer treatment to eliminate potential age discriminatory practice. Additionally, the 2009 Cancer Reform Strategy second annual report plans to publish data on patients over 75 (both mortality trends and interventions), which will give an indication of where problems occur and provide a basis for action by PCTs.

3.18 During the course of our review, there was significant media coverage of research showing the relatively poorer survival rates for women with breast cancer who are over 75[21]. Published research has shown how, once the grade and size of the tumour has been adjusted for, women over 80 have markedly poorer access to investigation and treatment than women aged 65 to 69.[22] Science will continue to progress and so the NHS and social care will need to continually review what is best practice in relation to providing age equality in services. One area that requires further work is the use of the so-called "frailty scoring systems" that help professional staff objectively assess the capacity of patients to undergo and benefit from healthcare interventions and thus avoid the perception that decisions are made based on patient's age rather than their need. In general, where it is possible to avoid using age as a criterion for providing care to an individual, by drawing instead on more pertinent and individualised evidence, age should not be employed.

3.19 Screening programmes play a crucial role in early identification and prevention and they often include specific age criteria. Our consideration of the evidence suggests that the current approach to screening for breast cancer will require further scrutiny by the Department of Health. Invitations to breast cancer screening are not currently sent to women aged under 50 and over 70 (shortly

19 Cancer Reform Strategy, DH, 2007, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081006
20 National Cancer Equality Initiative: http://www.cancerinfo.nhs.uk/
21 'Many UK Cancer Deaths Premature', BBC online http://news.bbc.co.uk/1/hi/health/8117561.stm;
22 Non-Standard Management of Older Women with Breast Cancer in the UK, Lavelle K., Centre for Cancer Epidemiology, 2007

to rise to over 73). Although there is evidence about the limited effectiveness of population screening in women under 50, there is a lack of definitive evidence that women over 73 will benefit from being invited to a screening programme (screening is available to women who are not invited if they request it)[23]. Of course, not being able to prove that screening will be a benefit to over-73s is not the same as proving that it definitely will not benefit women in this age group. ***We recommend that the Department of Health ensures that a programme of research is commissioned that enables the Advisory Committee on Breast Screening to advise on the upper limit of the breast cancer screening programme, and regularly updates the evidence.*** ***[Recommendation 3]***

Prevention Programmes

3.20 In March 2005, the Department of Health and partners launched the Partnerships for Older People Projects (POPPs). The aim was to improve health, well-being and independence of older people through a range of locally determined innovative projects. The 2008 review showed that the projects led to an improvement in the quality of life for service users and they were associated with a wider cultural change in the locality.

3.21 In July 2009, the Department of Health launched the Prevention Package to encourage people over 50 to access preventative health checks. In the South West, there has been a joint health and social care peer-review audit looking at dementia and falls services across the region and the economic case for preventing falls shows the benefits for both health and social care.

3.22 One of the key lessons from the local engagement events is the importance of involving people in the design and delivery of age-appropriate prevention programmes. The range of potential mechanisms to plan innovative solutions and deliver multi-agency services was highlighted in the engagement events, especially those in POPP pilot sites. The need to retain and expand such programmes locally was emphasised by participants in the local engagement events because of their potential to both deliver recurrent long-term savings as well as their impact on the quality of life of local people.

3.23 ***We recommend that health and social care organisations work in partnership to implement demonstrated best practice in prevention programmes that improve the quality of life of older people.*** ***[Recommendation 4]***

23 Clinical evidence from the International Agency for Research on Cancer and independent advisory committees containing experts across the screening pathway is used to suggest age ranges.

Conclusion

3.24 The examples set out above serve to illustrate that decision-makers and practitioners throughout the system, from local organisations through to the Department of Health along with its Arms Length Bodies and Advisory Committees need to be aware of the requirements of the legislation, including, in particular, the public sector equality duty.

3.25 The range of issues raised during this review highlights the need for increased awareness and action at all levels of the system: policy, commissioning, provision and individuals.

Timing of implementation and the role for exceptions

4.1 This review was asked to make recommendations about the timing of the implementation of the ban on age discrimination in health and social care. There is a power in the Equality Bill to provide that specified conduct or action does not contravene the ban on age discrimination (or, in other words, counts as an 'exception' to the ban). The review was also asked to consider whether such exceptions could be helpful in relation to health and social care.

4.2 In coming to conclusions on both of these matters, we have weighed up a wide range of quantitative and qualitative evidence. We have also considered discussions with the local NHS and social care organisations on the action required to make progress on implementing both the ban and the public sector equality duty. The challenge should not be underestimated but there has been good recent progress and the goal of age equality is strongly aligned with existing health and social care policies.

4.3 On timing, the Government's aim is that the public sector duty will come into effect in April 2011, and this will apply to health and social care. In looking at the implementation of the ending of age discrimination, the evidence has led us to the following conclusion: ***subject to the outcome of the consultation process on the age provisions in the Equality Bill undertaken by the Government Equalities Office, the Government should set the same commencement date for the ban on age discrimination in health and social care as in other sectors***[24]***. [Recommendation 5]*** This is based on our judgement of the changes that may be required to achieve compliance and the optimal balance between providing sufficient time to prepare and the need for momentum in working towards greater age equality.

4.4 We have considered whether we should recommend that the power in the Bill to create exceptions to the ban on age discrimination should be used to create any exceptions specific to health and social care. Broadly speaking, that power can be used in two ways:

- to remove areas wholesale from the scope of discrimination law, for example, by saying that the ban on age discrimination in the provision of services and exercise of public functions does not apply to "a function of the NHS" or to "health services of a specified nature";

- to create for specific areas the requirements that need to be satisfied for less favourable treatment to be lawful. In those specific areas, it is these specific requirements that apply, rather than the general requirement to

24 Subject to consultation, the Government envisages this date to be 2012. Other recommendations in this report that are linked to commencement have taken 2012 as the date of commencement.

show less favourable treatment to be a proportionate means of achieving a legitimate aim. Such specific requirements provide greater legal certainty about the conditions that need to be met than the standard "objective justification" proviso.

4.5 We have not identified any arguments for creating exceptions of the first kind: as we have explained earlier in this report, we see the aims of equality and discrimination law as entirely consistent with the ethos of health and social care.

4.6 ***We recommend that there are no areas within health and social care that should be removed wholesale from the scope of the ban on age discrimination. [Recommendation 6]***

4.7 We are not in a position to make a firm recommendation on whether exceptions of the second kind should be created, and have identified this as an area on which the Government needs to do further work. What is clear is that some national policies currently use age in determining who should receive particular health services (for example, flu vaccinations are targeted on people of particular ages, and breast and cervical cancer screening are targeted on women in specific age groups). We have examined these policies and are satisfied that the intention in using those age limits is to do what is justified. On that basis, it could be argued that there is no need to create exceptions. On the other hand, although the intention of those policies is to do what is justified, it is at least theoretically possible that the courts might find that in practice one or another of them has not satisfied the requirement for objective justification. There might therefore be a case for an exception, or exceptions, to spell out precisely which tests need to be satisfied for those policies to remain in place. This would provide greater legal certainty about the basis on which such policies should operate, and we do not think there would be anything wrong in principle with exceptions designed with this in mind. However, decisions on whether to create such exceptions will require further work on the existing basis for the current policies, and will also need to take account of what exceptions the Government decides to create from the age discrimination ban for other sectors.

4.8 It is possible that similar issues about the absence of definitive evidence on age explicit criteria apply to services in addition to breast cancer screening (see the discussion above in chapter three). We have undertaken a high-level analysis of the current arrangements and identified an initial list of such criteria (see the working papers for the review). The Department of Health needs to ensure that its arrangements for making and reviewing policies ensure that age limits are not adopted or retained except where they are justified. This will not be a one-off exercise, since, for example, the development of new technologies could affect judgements about what is proportionate.

4.9 In summary, we have not identified any specific services where we feel that there is a need for an exception in the absence of a clear objective justification, but we are not the experts in specific service areas. ***We recommend that the Government should consider further whether any more specific exceptions are needed for health and social care. We do not think there is anything wrong in principle with such exceptions, but we have not identified a compelling need for any. [Recommendation 7]***

4.10 ***We recommend that the Department of Health should set out how it and the Advisory Committees and Executive Agencies that it sponsors will ensure public confidence by assessing age-based criteria in a transparent manner, leading to changes in policy if required. Arms-length bodies, such as Executive Non-departmental Public Bodies, should satisfy themselves that any age-based criteria they apply comply with the new legislation. [Recommendation 8]***

Resources and commissioning

5.1 In developing our conclusions on resources we have considered the financial challenges that health and social care services are going to face in the coming years. In a period of tighter funding than in recent times, people are often concerned about fairness in the allocation of resources. Age equality is one aspect that should be seen alongside other inequalities. In addressing the financial challenges, organisations will need to use service redesign to free up resources to provide better, more equitable, care reduce waste and prevent inefficiency. Personalisation enables a closer match of resource and need and, in some situations, redistribution of resources will be required to implement this agenda. We have developed our conclusions in the context of the agreements about finance for the health and social care system, including the New Burdens Doctrine.

5.2 The call for evidence and discussions with stakeholders raised a number of key questions linked to resources and commissioning:

- Are resource allocation formulae fair in respect of age?
- Is the use of cost effectiveness measures such as QALYs fair to all age groups?
- Does commissioning serve the needs of all age groups fairly?
- Are care packages and charges as they are employed in social care discriminatory?

5.3 In broad terms, resources take two steps to get from taxpayers to service users. Firstly through the allocation process which determines how much local organisations receive for their populations, and secondly through the conversion of resources into the services that people need at a local level. This conversion takes place through commissioning and the determination of the services, packages or budgets an individual receives; the local engagement events have emphasised the importance of transparency in these processes.

5.4 In our analysis of resource issues we have looked at both steps, focusing on the outcomes for individuals. Different levels of spending between age groups are not, in themselves, proof of discrimination but they do indicate the need for further analysis and challenge. The relevant statutory bodies need to review their policies and spending against the new law and identify where the differences justifiably reflect differences in need and cost. Where this test is not met, organisations are likely to need to take action to implement change.

5.5 The broad conclusion of our analysis is that none of the mechanisms we have considered is inherently discriminatory or detrimental to achieving the public sector equality duty as it relates to age. There is, however, an ongoing responsibility on those who use and develop such mechanisms to ensure compliance with the requirements of the Equality Bill. In the process of commissioning services and determining packages, less favourable treatment can arise. It is therefore vital that local organisations explicitly consider and avoid age discrimination in developing these.

The allocation process-funding formulae

5.6 The allocation to Local Authorities of funding for adult **social care** is based on two Relative Need Formulae (RNF), one for older people and one for younger adults. They are designed to reflect the relative needs of individual authorities in providing or arranging services for their populations[25]. The younger adults' formula takes account of population numbers, deprivation indicators and local costs. The older people's formula takes account of population numbers, age and deprivation indicators, sparsity, low incomes and local costs.

5.7 The two formulae are weighted together on the basis of the historic division at national level of expenditure between older people and younger adults. This means that previous disparities in resourcing can be, to some extent, reinforced.[26] These disparities are often the result of a number of different factors. Where such differences reflect differences of aspiration for older people as compared to younger people, that is likely to be much more difficult to defend. ***We recommend that the Department of Health should review the relative weighting of the two formulae before 2012. It should also ensure that this and future reviews of the formulae ensure compliance with the ban on age discrimination and the public sector equality duty. [Recommendation 9]***

5.8 Eighty per cent of resources in **health** are allocated to PCTs on the basis of the relative needs of their populations. The age profile of the local population (which is a good predictor of need) is one of the factors that determines the allocation in health. As in social care, if some groups have consistently been

25 Relative needs are the needs of one local authority or PCT relative to another in providing services to their population. For example, the size of the population is one factor in the local authority's or PCT's need to provide services, deprivation is another indicator.

26 It seems unlikely that a single RNF allocation formula for all adult social services would be satisfactory. Key reasons are:

- An adjustment for low incomes is important for older service users many of whom contribute to the costs of their care through user charges but not for younger adult services users who mostly do not have sufficient resources to contribute user charges;
- The determinants of need may differ between younger adults and older people: for example, while disability is associated with lower socioeconomic groups among older people, severe learning disability is not associated with any one socioeconomic group.

This suggests that a single formula would probably not be as fair as the current two formula arrangement to Local Authorities with a population age distribution that differed markedly from the national distribution.

unwilling or unable to access services, the formula will not fully reflect their needs. A separate health inequalities formula adjusts for this using disability free life expectancy. The introduction of this formula has reduced the weight given to age as a factor in resource allocation. We have not received evidence that suggests that this change is discriminatory based on age and we are confident that the oversight of the formula by the independent Advisory Committee on Resource Allocation (ACRA) ensures the formula is robustly constructed. ***We recommend that the Department of Health formally asks the Advisory Committee on Resource Allocation (ACRA) to ensure that its future recommendations comply with the age discrimination ban and the public sector equality duty in its ongoing work.*** ***[Recommendation 10]***

Cost-effectiveness and QALYS

5.9 Cost-effectiveness measures such as QALYs (Quality Adjusted Life Years) are used to inform decisions about resource utilisation in healthcare, most notably those of NICE (National Institute of Health and Clinical Excellence), the body which makes recommendations about the cost-effectiveness of different drugs and treatments.[27]

5.10 The Department of Health commissioned a review of cost-effectiveness analysis and ageism from Leeds University, which looked at QALYs.[28] QALYs are a combined measure of the benefits in terms of length of life and health-related quality of life changes that follow from a treatment. Cost effectiveness analysis compares these benefits with the costs of treatment to enable the quality and cost of different health interventions to be compared.

5.11 Some researchers and commentators have expressed concern that QALYs discriminate on the basis of age, because older people are likely to have fewer 'life years' ahead of them. We recognise that, in theory, some people can be treated less favourably as a result of using QALYs.[29] This is an area of lively debate but we have not found alternatives to QALYs that would be practical and less discriminatory in allocating resources. We would therefore support the continued use of QALYs with specific attention paid to situations in which the use of QALYs could result in less favourable treatment.

27 PCTs are obliged to fund forms of treatment that NICE approves through its technology appraisals, for example, drugs. Other forms of NICE guidance, such as the clinical guidelines that set out best practice for treatment of certain conditions, are not mandatory.

28 *Cost-effectiveness analysis and ageism: a review of the theoretical literature*, Richard Edlin, Jeff Round, Christopher McCabe, Mark Sculpher, Karl Claxton, and Richard Cookson, June 2008

29 NICE uses QALYs as part of its methodology for assessing the overall clinical and cost-effectiveness of treatments and interventions. As a matter of principle, NICE does not refer to age in guidance recommendations unless there is evidence that age is a good indicator of either risk or benefit from treatment. If age is referred to, the reasons for the reference must be explained. By applying this principle, NICE avoids the risk of age discrimination from use of the QALY. Other safeguards are systematic consultation procedures, transparency in decision-making, and consideration of age as a factor in equality impact assessments for every item of guidance.

5.12 We have also considered arguments for adjusting QALYs to address what some researchers have identified as inadequacies:

- Broadening the definition of health states to capture small improvements. This is currently being addressed by the relevant agency (Euroqol), and should help to make QALYs more sensitive to small improvements.

- Including non-health benefits (eg- saved carer time). This has some attractions, but the inclusion of all non-health benefits would entail inclusion of patients' productivity, which would give rise to many ethical issues. Further work is being carried out by York University on this topic.

- Use of age banding for NICE technology appraisal to get more age-sensitive results. We are concerned that incorporating age explicit criteria could result in age bands being used inappropriately, where information on the individual's condition was far more relevant to whether a treatment should be used.

5.13 We note the methodological debate and ***recommend that that the Department of Health and the NHS review the use they make of QALYs and other similar support tools to inform their decision-making prior to the Equality Bill coming into force.***

[Recommendation 11]

Commissioning services for populations

5.14 Commissioning is the process of ensuring that the health and care services provided effectively meet the needs of the population. Good commissioning processes are essential for providing a non-discriminatory service. The existing guidance for commissioning in health and social care sets out a robust process for identifying need and obtaining the services required in a particular area. As well as being good practice, these processes will enable Local Authorities, PCTs and Practice Based Commissioners to explain their commissioning decisions to local people and stakeholder organisations.

5.15 All commissioners in health and social care need to be able to demonstrate to the local population what they are doing to meet their responsibility for delivering non-discriminatory services through:

- Understanding local need. Commissioners need to ensure that the joint strategic needs assessment (JSNA) clearly addresses age equality, along with other areas of potential inequality. A good understanding of local needs is essential in ensuring that services are designed and delivered in a non-discriminatory pattern. From our work in the South West we are clear that there is a particular need to focus on groups that might experience dual or multiple discrimination, where two or more of the protected characteristics are combined (for example, services for people with

dementia who also do not speak English that do not meet the needs of the person in respect of their age or, indirectly, their race because of a lack of translation services). We explored issues of ethnicity and religion and belief combined with age and we heard examples of how age affected need in rural areas. In some situations, additional efforts may be needed by commissioners to gather and analyse experiences and needs of older people and their carers, since they may find more conventional engagement methods inaccessible.

- Commissioning the appropriate volume and quality of services to ensure age equality – current services often reflect historic patterns, whilst demand, need and aspirations of local people change. Commissioners therefore have to analyse data on the current patterns of service by age and ensure that service provision meets the needs identified in the JSNA. The new legislation will require closer scrutiny to determine whether age-differentiated patterns of provision can be objectively justified or result in unfavourable treatment based on age. We have commissioned the University of West of England to review the JSNAs in the South West in relation to age equality and look at examples of indicators that show the age patterns of service provision in a locality. Commissioners will want to use these to help ensure that their services are fairly meeting the needs of different age groups.

5.16 These challenges are well recognised and there is work to increase the competency and capacity of commissioners in working with their local populations. With the introduction of the legislation it will be critical for commissioners in health and social care to mainstream thinking about addressing and preventing age discrimination (along with other forms of discrimination) and promoting equality into existing processes not just as a one-off exercise but to reflect changing technology and needs in their area.

5.17 In the NHS, the World Class Commissioning (WCC) framework is designed to support commissioners. The commissioning assurance system will drive performance improvement and the development of PCTs and Practice Based Commissioners. A number of the competencies within the WCC commissioning framework could be linked more explicitly to ending

discrimination against the eight protected characteristics[30]. While the most recent amendments to competencies 3 and 6 have made helpful progress in this direction, the next round of amendments should consider further strengthening the competencies, and/or the WCC framework as a whole, in the light of the Equality Bill. The collaboration between the Departments of Health and of Communities and Local Government will help build capacity locally to support joint commissioning.

5.18 ***We recommend that the Department of Health should ensure there are clear and emphatic references to ending discrimination in relation to the eight protected characteristics (including age) and advancing equality in the 2010/11 World Class Commissioning assurance process. [Recommendation 12]***

5.19 The capacity and capability of commissioning functions across the country varies greatly but increasingly health and social care are coming together to commission services. Joint commissioning arrangements for older people, and for other client groups, vary between localities, but there is a widespread wish to bring together commissioning capacity to focus on the needs of individuals as well as on meeting population needs.

Commissioning care for individuals

5.20 Personalised services are being introduced in both health and social care and can be very effective in enhancing equality. People with complex and varied health and care needs require packages of care tailored to their specific needs. Especially in Local Authorities, there is experience working with service users to assess their needs and then designing packages. From our discussions with stakeholders and from the evidence submitted to the review, there is a consensus that over many years this process has tended to provide more extensive packages of care to younger people than

30 The relevant competencies are-
- Competency 2: work with community partners. Creation of Local Area Agreement based on joint needs; Ability to conduct constructive partnerships; Reputation as an active and effective partner.
- Competency 3: engage with public and patients. Influence on local health opinions and aspirations; Public and patient engagement; Improvement in patient experience.
- Competency 5: manage knowledge and assess needs. Analytical skills and insight; Understanding of health needs trends; Use of health needs benchmarks.
- Competency 6: prioritise investment of all spend. Predictive modelling skills and insights to understand impact of changing needs on demand; Prioritisation of investment and disinvestment to improve population's health; Incorporation of priorities into strategic investment plan to reflect different financial scenarios.

For further information on world class commissioning, see http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/DH_083204. See also the *Commissioning framework for health and well-being*, DH, 2007- http://www.dh.gov.uk/en/PublicationsandstatisticsPublications/PublicationsPolicyAndGuidance/DH_072604

to older people with the same needs.[31] We have also heard about the needs of carers where there is scope to improve how the specific needs of both younger and older carers are met. **We recommend that Local Authorities review their assessment procedures and the resulting packages of care and funding arrangements for both service users and carers in preparation for the new legislation focusing on the outcomes that are delivered for service users and their carers.** ***[Recommendation 13]***

5.21 In terms of assessment, local authorities will want to consider using a common assessment for all categories of client. This could be either an identical assessment or an assessment that covers the same types of need and gives the same weighting to these for all groups. It is important that people of all ages are given the same opportunity to express their aspirations and have these taken into account. Different individuals will have different aspirations and a personalised, non-discriminatory assessment will enable these to be identified.

5.22 Local Authorities have different approaches to developing the packages of care offered to people. As part of ensuring that these packages are not discriminatory, Local Authorities will want to consider:

- For the purposes of individual budget setting, following the new guidance from the Association of Directors of Adult Social Services (ADASS), *Common resource allocation framework*, that recommends using a single resource allocation system (RAS) for all client groups and giving a transparent, evidence based justification for final budgets that differ from the budget indicated by the RAS. This approach can be used to provide people with non-discriminatory services and can be used to explain why there may be legitimate differences in service provision. However, the detail of how the local authority actually implements the process is crucial as historical and potentially discriminatory service patterns can remain despite process changes.

- For clients who receive a package of services, rather than a budget, assessing whether individuals of different ages get different packages and the extent to which any differences can be objectively justified. If packages do discriminate, then money may need to be reallocated between client groups.

- Developing markets to encourage the supply of the services that meet clients' needs through an age equal pattern of services.

31 In comparing packages it is important to compare the extent to which they meet people's needs. The financial value of packages for people with similar needs, is not alone a good indicator of discrimination as 1) people have different aspirations that they would like social services to meet and 2) it can cost different amounts to commission services for people of different age. However, both of these factors leading to differences in the value of packages need to be justified.

- In modernising their services, actively consider impacts on different age groups through good use of Equality Impact Assessments.

5.23 As part of the resource pack associated with this review, the Social Care Institute for Excellence is developing good practice guidance that will describe in more detail how Local Authorities can meet these challenges. The scale and nature of the challenge will be different for each council so we suggest that Local Authorities will want to work with their local stakeholders to help them identify what may need to change and then assess the resource implications locally for this.

5.24 With the focus on long-term conditions, the NHS has become more active in using techniques that identify current and potential patients who will need intensive support packages to help them maintain independent healthy lives. Practice Based Commissioners play a vital role in designing and supporting these packages to meet the existing and future needs of individuals in collaboration with their social care colleagues.

Charging in social care

5.25 This area received little comment in our call for evidence. The recent announcement by the government that people whose needs are categorised as "critical" will receive free home case ensures equal treatment for all age groups in this category. For those in other categories there is some difference in charging for home care as charges take into account a person's pension but not their earned income. This has been justified on grounds that if charges were made against income people would be deterred from seeking opportunities to work. Employment is considered to have a positive effect on a person's wellbeing as well as their income and so is actively encouraged.

5.26 In the longer term, there may be significant changes to the way social care is funded, as set out in the green paper, *Shaping the future of care together*.[32] Work on age equality provides an essential building block in the wider work on social care reform and impacts of funding across all equalities strands will need to be considered carefully through the current consultation and following work to develop the policy.

32 *Shaping the Future of Care Together*, DH 2009, http://careandsupport.direct.gov.uk/greenpaper/

Seeing the person, not the age: attitudes, behaviour, culture and leadership

6.1 A large number of stakeholder organisations and individuals told us that attitudes are among the most important causes of age discrimination. Many of the experiences of age discrimination that we have looked at have involved insensitive behaviour, some of which is rooted in ageist attitudes[33]. Most examples of age discriminatory behaviour appear to be matters of thoughtlessness and misplaced assumptions, often reflecting those in wider society and are not the product of avowed prejudice[34]. In one sense, this is positive: tackling age discrimination is not, for the most part, about tackling and preventing deeply held prejudice. It also, however, means that a great many of the people and organisations who are behaving in this way do not recognise their behaviour as discriminatory.

6.2 Commissioners and providers of health and social care in a locality will want to work together to focus on how they can shape behaviour both to tackle age discrimination and promote age equality. Changing behaviour is clearly a challenge, but evidence from within and beyond the health and social care system shows it can be done even if some of the work that is needed to shift underlying attitudes will take some time and rely in part on wider forces in society.

6.3 There is clearly still some way to go in tackling ageist attitudes, and in particular those that are not explicitly negative[35]. However, there is a strong basis in the values held by individuals, professional organisations and service organisations for treating people well whatever their age. In addition, changing behaviour need not rely solely on changing attitudes. Changing and shaping the environment, including through strong, visible leadership can have a real impact on behaviour, bringing more individualised shifts in attitudes in its wake.

Shaping norms: the role of professional regulators

6.4 For many people who work in the NHS and social care, their professional affiliation and the values attached to it are a critically important factor in shaping their behaviour. The role of the professional regulators is therefore

33 See "Acopia' and 'social admission' are not diagnoses: why older people deserve better', David Oliver, *J R Soc Med 2008*: 101; 168-174. See also 'Geriatric medicine: changing staff attitudes', Dr David Oliver, *Health Service Journal*, November 2007, http://www.hsj.co.uk/geriatric-medicine-changing-staff-attitudes/262440.article

34 See 'Accommodative speech and terms of endearment: elements of a language mode often experienced by older adults', Brown and Draper, *Journal of Advanced Nursing*, 2003; 41(1): 15-21; Harry Cayton, 'The alienating language of healthcare' *J R Soc Med* 2006

35 For example, assuming that depression is often a 'natural' feature of ageing can be accompanied by a highly compassionate attitude towards those suffering it, but is also likely to lead to a limitation in therapeutic responses that may constitute 'unfavourable treatment'.

central to the long-term eradication of age discrimination and the attitudes behind it. We can already point to a great deal of helpful material in the codes of practice used by, among others, the General Medical Council, General Social Care Council, Nursing and Midwifery Council and the Health Professions Council. The General Social Care Council Code of Practice, for example, requires social care workers to treat each person as an individual, promote equal opportunities for service users, communicate in an appropriate, open, accurate and straightforward way, and challenge and report discriminatory behaviour[36]. These requirements offer a clear indication to individual professionals of what is expected of them, and a source for education and training. It also sets out clear expectations and standards for the public.

6.5 As the move toward implementation of revalidation continues, doctors will need to demonstrate their conformity with the relevant professional standards more frequently than before, and this should help to reinforce the need to treat people well whatever their age. Given the importance of professional regulators in shaping the norms that, in turn, shape attitudes and behaviour, ***we recommend that all professional regulatory organisations will need to review and, if necessary, revise their standards, codes of conduct and education programmes to advance equality and to ensure that age discriminatory behaviour is clearly identified as unacceptable and a failure in professional standards.***

[Recommendation 14]

6.6 We were particularly impressed by the recently published Nursing and Midwifery Council (NMC) publication *Guidance for the Care of Older People,* which took the contents of the NMC code and drew out in clear language what this meant for the care of older people[37]. Professional regulatory organisations may want to build on this example and develop guidance on non-discriminatory care; this may be more effective than adding references to older people in professional codes and standards.

6.7 We look to the relevant professional bodies to build on existing work to support professionals to comply with the law and meet their wider obligations to the people they care for, but we should not lose sight of the need for individual professionals and practitioners to take personal responsibility. All social care and health professionals and practitioners will be required to adopt a non-discriminatory approach in involving patients/service users and their carers.

36 GSCC Code of Practice- http://www.gscc.org.uk/codes/. See also the standards of proficiency set out by the Health Professions Council- http://www.hpc-uk.org/aboutregistration/standards/, the Nursing and Midwifery Council code- http://www.nmc-uk.org/aArticle.aspx?ArticleID=3056 and the General Medical Council publication 'Good Medical Practice'- http://www.gmc-uk.org/guidance/good_medical_practice/index.asp.

37 NMC, 'Guidance for the Care of Older People', 2009, http://www.nmc-uk.org/aArticle.aspx?ArticleID=1673.

Education and training

6.8 An understanding of the new legal requirements set out in the Equality Bill and, crucially, of how these requirements align with the professional values and ethical obligations of health and social care professionals, needs to be clearly conveyed by education and training programmes at all levels of the system and at all stages in the careers of health and social care professionals. All health and social care education and training curricula and programmes will need to be delivered in accordance with the public sector equality duty and the age discrimination ban and this will affect commissioners, providers and assurers of education. ***All organisations responsible for education and training in health and social care will need to ensure that their curricula and programmes enable staff and trainees to apply the law effectively in time for its commencement. We recommend that the providers of education develop ways of involving older people in the delivery of education programmes, especially to trainees at an early stage in their learning.***

[Recommendation 15]

6.9 The continuing training and development of staff by their employers are also crucial in shaping attitudes and behaviours and age awareness, especially for staff who are not registered by a professional body (such as healthcare assistants and administrative staff). Age equality training was considered as essential by those attending the local engagement events. Their feedback was that this is best addressed as part of training to support the implementation of personalisation and dignity for people of all ages as well as being part of wider equalities training. Thus the resource pack is being designed to support local organisations to make these linkages. ***Local statutory organisations should build into their contracts with providers of training programmes (including third sector and private organisations) the need for an explicit focus on age equality that supports staff in providing high quality services to people of all ages.***

[Recommendation 16]

Leadership and organisational culture

6.10 Evidence shows that good leaders can make a real difference in shaping the culture of their organisation to promote age equality and prevent age discrimination[38]. Their responsibility is twofold. Leaders need to ensure that the systems and processes they are responsible for are geared to delivering and demonstrating age equality. Even more importantly, leaders need to be visible and vocal on this issue: age discrimination, like other forms of discrimination, can proliferate when leaders fail to make it clear that it is not to be tolerated: silence can be read as permission. ***Leaders of health and social care organisations, including the boards of those***

38 See the Healthcare Commission report 'Equality in later life: a national study of older people's mental health services', 2009, p18.

organisations and Elected Members, will want to set out a clear commitment to their staff and the wider public to meeting the requirements of the age discrimination ban and the public sector equality duty and demonstrate how the health and social care sector can show leadership in tackling ageism in society. [Recommendation 17] Visible, board-level engagement with this agenda will be crucial. Organisations may also want to consider the use of board-level champions.

Being seen, being heard

6.11 Age discrimination allows a single characteristic to typify a person and can serve as the basis for unhelpful assumptions and a dismissive attitude. Addressing and preventing age discriminatory behaviour is about perception as well as values: it requires seeing members of different age groups as individual people with potential and with aspirations and hopes[39]. The new public sector equality duty in the Equality Bill provides a legal framework for this, and the wider health and social care agendas of personalisation and high quality care (which includes ensuring positive experiences of care) will also serve to reinforce the need to see the person and not the age.

6.12 In addition, the health and social care system needs to base its approach to people on their actual needs, preferences and aspirations, not assumptions about them derived from age. NHS organisations and Local Authorities have a range of statutory duties to involve people of all ages – we received strong messages that older people and their representative groups wanted to be involved, though they did not want to be part of tokenistic consultations but meaningfully engaged from the beginning, in co-producing and co-designing services and in the monitoring and evaluation of success. There is scope for the NHS and LAs to do more in understanding the age-specific wants and aspirations of different groups, especially groups that are seldom heard and those that combine several of the protected characteristics and so are at risk of discrimination because of more than one protected characteristic.

6.13 The recent publication *Building a Society for all ages* set out a cross-government agenda for working towards a society where old age is no longer perceived as a time of dependency and exclusion, and where people are not defined by their age[40]. We must not let prejudice prevent us harnessing the skills and experience of our older population. A society that sees older people more positively valuing, for example, the huge contribution that many older people make as carers and volunteers, is much less likely to be discriminatory towards them. SHAs and the Department of Health teams

39 See, for example, the report *See me, not just the dementia,* CSCI 2008. See also 'Justifiable depression': how primary care professionals and patients view late life depression? A qualitative study', Burroughs, Lovell et al, *Family Practice* 2006; 23: 369-77; 'Value judgements in the decision-making process for the elderly patient', Ubachs-Moust, Houtepen, Vos, ter Meulen, *J Med Ethics* 2008; 34: 863-868.

40 *Building a society for all ages,* July 2009, http://www.hmg.gov.uk/buildingasocietyforallages/download.aspx. For involvement of older people see also *Review of Older People's Engagement with Government*, John Elbourne Report to Government, November 2008

in the regions therefore need to ensure that they are active partners in the implementation of *Building a Society for All Ages,* which promotes the active involvement and empowerment of older people in services and a renewed focus on the preventative agenda, as people plan for later life.[41]

6.14 In some situations, seeing the person may involve explicitly ignoring age when decisions are made about them. Just as it is common practice in employment to "shortlist" candidates for a job "blind" to their personal characteristics, we heard of some Primary Care Trusts who adopted a similar approach to individual case reviews. While this is clearly not appropriate in all circumstances, it has the potential to help decision-makers remove the possibility of age discrimination- and the perception of it- from the allocation of care in at least some situations.

6.15 Involving people in the planning, design and commissioning of services is a crucial part of promoting age equality and identifying and eliminating age discrimination. It is equally important for organisations to listen and learn from comments, feedback and complaints. The social care and NHS system introduced a new common complaints system in April 2009, which focuses on speedy local resolution and improving service delivery. The approach in each case needs to be based on the needs of the individual and resolved according to the outcome that the complainant wants. This offers the potential to enable concerns about possible age discrimination to be addressed quickly, errors corrected and lessons learnt. We recommend that ***local NHS and social care commissioners and providers, and the people that work in them, consider how they can use the new NHS and social care complaints process to achieve rapid resolution of individual instances of potential discrimination. [Recommendation 18]***

Conclusion

6.16 Age discrimination is rooted in the behaviour and attitudes of health and care organisations and staff – and wider society. Tackling it will require addressing issues at the level of systems and processes, but also changes to the ways in which people within and beyond the system think about and behave towards people of different ages. Building on the values shared across the system, the professionalism of individuals and with effective leadership at all levels, this is a challenge that can be met.

41 The Partnerships for Older People's Projects offer an example of prevention and promotion of health and well-being- see Partnerships for Older People's Projects, 2007-2008, http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/PartnershipsforOlderPeopleProjects/index.htm

Making it happen locally: listening, improving, assuring

Principles for effective implementation

7.1 One of the important tests of whether age discrimination has been ended is whether people locally believe that their health and social care systems are fairer and provide services based on need and not age. From our engagement work, particularly in the south west, the particular issues vary from service to service and from locality to locality so PCTs and Local Authorities have a crucial role as the leaders of the health and social care system in identifying the local priorities and producing action plans to prepare for 2011 and 2012.

7.2 Our terms of reference included recommendations on the key actions that the health and social care system should take to make demonstrable progress. We have identified three key principles for effective implementation:

- A need for **close collaboration between services and organisations** in ending age discrimination and promoting age equality. This applies both across the health/social care boundary (and more broadly the NHS/local authority boundary), between different services and sectors within health and within social care and to work with key third sector and private sector organisations. The problems that organisational boundaries can cause patients, service users and carers are often particularly pronounced in relation to age discrimination because many people who are at risk of experiencing discrimination have complex needs and require services from different agencies. We have heard of examples of age discrimination at the crucial points of assessment and referral between services and in the interface with other local services, such as benefits support.

- A commitment to **focus on age equality within the core clinical and business processes**. The existing systems and processes often struggle to deal with the diverse needs of people of different ages, in particular the requirements of frail and older people with co-morbidities and complex health and care needs. Ending age discrimination does not require a new set of policies but, along with work on the other protected characteristics, it can be built into the core process of Local Authorities and NHS organisations. However, the need to address age discrimination in service provision will be a new legal requirement – so it will require organisations to adopt a focused and purposeful approach to understanding the local issues and tackling them as part of implementing key organisational priorities, such as delivering *High Quality Care for All, Putting People First,* Quality Innovation, Prevention and Productivity and *Shaping the Future of Care Together*.

- A commitment to **demonstrating progress to local people.** One of the messages from the local engagement events was that people want to be involved at an early stage so that they could make an informed judgement on progress rather than consulted towards the end of the decision-making process. Thus Local Authorities and PCTs will build on the work they have done following the Elbourne Review to develop age-appropriate mechanisms that help local people judge that services are provided fairly to service users of all ages.[42]

Supporting change-scrutiny, analysis, action

7.3 Taking these principles along with what people told us locally about how best to apply them in practice, the review team are working with local partners to develop a resource pack that will help develop the local implementation plan. There will be a toolkit that could be used in 2010-11 to help organisations to audit their current position in relation to age discrimination and promoting age equality. This will use a range of information from different sources to identify the gaps that need to be addressed before the law comes into effect. The conclusions will provide the basis for a dialogue with local people, and lead into a local implementation action plan that can inform the commissioning process and provider improvement programmes.

7.4 To support this process, the review team and the Department of Health have commissioned two linked good practice guides, one for the NHS and the other for Local Authorities. These are being produced in partnership with local statutory and third sector organisations, mainly but not exclusively in the South West. Drafts of these three products will be consulted upon between November and February and during the next phase of their development we would like to see other organisations contributing towards its improvement. NHS South West and the Government Office South West will continue to oversee the further development of the resources so they are available for use in 2010-11.

7.5 These resources will provide a basis for developing a local process for achieving, maintaining and demonstrating compliance with the age discrimination ban and the public sector equality duty. ***Local social care and health commissioners and providers will want to work together to implement the age provisions in the Equality Bill. We are producing a resource pack to support local communities and recommend that the local approaches share the following features/ outcomes:***

- ***Led by PCTs and LAs, with joint audit of services, systems and processes across health and social care;***

42 Review of Older People's Engagement with Government, John Elbourne Report to Government, November 2008

- ***Joint action planning across health and social care that sets out how local organisations will meet the public sector equality duty and comply with the age discrimination ban;***

- ***Work with NHS, LA, third and independent sector providers and those working in them to embed actions in provider improvement plans;***

- ***Assessment and agreement of the local resource consequences of implementation within local funding parameters;***

- ***Involvement of members of the public in the work through Local Involvement Networks (LINks), forums and other networks and discussion of the conclusions of the local analysis by NHS Boards and Elected Members in public;***

- ***Use the local scrutiny processes and bodies such as Health Overview and Scrutiny Committees to provide transparency and build public confidence;***

- ***Build on existing approaches to implementing equalities and quality improvement but recognise that the age provisions in the Bill are a new requirement.*** ***[Recommendation 19]***

7.6 Local health and social care organisations will also need to ensure that appropriate links are made with other aspects of self-assessment and organisational development linked to commissioning and quality improvement. This is likely to include, where appropriate, the use of equality impact assessments and involve the implementation of equality scheme actions.

7.7 As the NHS and social care move in to a more financially challenging context there will be a major drive to improve quality through the prevention of waste and harm and increased productivity and value, which is called "Quality, Innovation, Productivity and Prevention" (QIPP) Programme. We recommend that ***the Department of Health and the health and social care system ensure that work to prevent harm and waste and spread innovation within the system should be designed to help promote age equality and that measures to end age discrimination are implemented so that they improve quality and productivity.*** ***[Recommendation 20]***

Conclusion

7.8 By working in partnership, looking at the issues in sufficient breadth and depth and engaging local people effectively in the process, local organisations will be able to make tangible and rapid progress in tackling age discrimination.

National action to lead and support change

8.1 Policy and legislation alone will not remove age discrimination from the health and social care system. There is, however, an important role for national leadership in supporting change within the system.

8.2 We have identified three crucial forms of support and leadership that should be provided at a national level:

- Making the case for change and standing up for the provision of high quality services to people of all ages;
- Ensuring national support in relation to data collection and the regulatory systems; and
- Ensuring national support in relation to knowledge and evidence to inform good practice.

Leadership throughout the system

8.3 The Equality Bill is, of course, a powerful statement of intent and leadership in itself, but the Department of Health will also need to ensure that the public sector equality duty becomes a mainstream part of policy formation. Departmental Equality Impact Assessments will enable this process but the leadership of the NHS and social care system has the opportunity to speak up about the unacceptability of age discrimination and commend the examples of good practice to the system.

8.4 ***We recommend that the Department of Health and the wider system ensure the use of tools such as Equality Impact Assessments to ensure compliance with the age discrimination ban and the public sector equality duty in all new policies. [Recommendation 21]***

8.5 The newly established Equality and Diversity Council has the potential to play an important role in providing assurance on system-wide improvement on equality and diversity issues. Although newly established, ***we recommend that the Department of Health develops a joint assurance process for social care and health to demonstrate progress with implementing the age equality provisions of the Equality Bill. The Equality and Diversity Council should consider how to support this process to ensure it is aligned with other assurance processes covering health and social care. [Recommendation 22]***

8.6 ***We also recommend that Local Authorities use the Joint Improvement Partnership process to share learning and progress, thus ensuring linkage with the implementation of Putting People First.*** ***[Recommendation 23]***

National support: data and regulation

8.7 High quality data is essential in guiding improvement activities and demonstrating progress both within the system and to the public. We have explored ways in which the use of quantitative data can stimulate improvement but have been frustrated by variable data quality, especially in social care. We note that producing and sharing benchmarking information both improves data quality and performance. National leadership can drive this forward thus ***we recommend that the Department of Health should work with the Health and Social Care Information Centre to explore how to construct an age-specific dataset to support the resource pack and help local organisations analyse and monitor patterns of service provision by age. This must link into wider work on indicators, including the programmes of the Public Health Observatories and the National Indicator Set.*** ***[Recommendation 24]***

8.8 In addition, the performance measures used by government and by statutory agencies should be compatible with the new legislation. The current set of NHS performance indicators, Vital Signs, are due to expire in 2011 and include explicit age cut-offs in relation to cancer and coronary vascular disease mortality. The social care indicators that are part of the wider National Indicator Set for local government also include data on services for different age groups and will be revised for 2011 onwards. ***We recommend that future performance measures that are both proportionate and targeted should be developed in accordance with the age discrimination ban and the public sector equality duty. [Recommendation 25]*** This may well mean avoiding at least some explicit age cut-offs.

8.9 Organisations with a responsibility for ensuring quality across the health and care economy, including SHAs, regulators and inspectorates will want to consider how to incorporate the requirements of the new legislation into their work and how best to co-ordinate their work to support local organisations to make good progress in tackling age discrimination and meeting the public sector equality duty. ***We recommend that all relevant national regulatory organisations, especially the Equality and Human Rights Commission and the Care Quality Commission should work together and with the Department of Health to ensure that a shared understanding of the implications of the law is the basis for registration, inspection, regulation and assessment of the health and social care system.*** ***[Recommendation 26]***

National support: research and evidence to promote good practice

8.10 Commissioning and delivering age equal services needs to become incorporated into the way in which the NHS and LAs work. Equality Impact Assessments will help enable this need but a range of national organisations are well placed to support the identification of good practice in implementing age appropriate services and tackling discrimination. The Department of Health and this Review have worked together to commission a resource pack for both health and social care in relation to age equality. ***The Department of Health should ensure that an up-to-date pack of resources, including good practice material, is available to health and social care organisations to support them to meet the requirements of the Equality Bill relating to age, and consider whether to identify national centres of expertise to co-ordinate work at a regional level to implement the provisions of Equality Bill. [Recommendation 27].*** This would build upon the work in the South West to accompany the review.

8.11 We would also support the commissioning of further work to drive forward the development and spread of good practice in how health and social care organisations can work together to personalise services.

8.12 Publicly funded research may only use specific age groups where there is a robust reason for this. Age groups have been used to focus public research in a way that promotes equality.[43] Evidence suggests that efforts by the Department of Health, Medicines and Healthcare products Regulatory Agency (MHRA) and European Medicines Agency (EMEA) have had some

43 The National Institute for Health Research does not provide support, directly or indirectly, for research from which older people are inappropriately excluded; and local, multi-centre, and national research ethics committees ensure that older people are not excluded from research concerned with the diseases from which they may suffer. The Medical Research Council similarly requires that, in full proposals, any proposed lower and upper age limits for trial participants should be justified on scientific grounds. As a result, there should normally be no upper age limit on recruitment. Certain trials supported by the NIHR Cancer Research Network are specifically designed for older people e.g. PRIME II (breast), FOCUS II (colorectal), and the *Cancer Reform Strategy*, DH, 2007 states 'Most clinical trials focus on patients under the age of 65, meaning that less data are available on the efficacy of treatment in older people. We believe that later stage trials should be conducted in groups who would be most likely to be treated with the medicines in question. We will work with the NCRN to develop ways of encouraging more clinical trials to include older people. We will also encourage medicines' regulators and industry to work together so that the use of age as an exclusion criterion in cancer clinical trials is avoided wherever possible'.

success in encouraging companies to include older people and people with co-morbidities in commercial clinical trials.[44]

8.13 A recent report, "Rejuvenating Ageing Research" from the Academy of Medical Sciences, suggests that some problems remain. It highlights the barriers to older people participating in clinical trials and the structure of research focusing on specific diseases rather than the process of ageing.[45]

8.14 Under the Equality Duty it is necessary to promote equality and having high quality research in all areas is an important part of this. ***We therefore call upon the Department of Health through the NHS National Institute for Health Research and its school for social care research to review the relevant guidance to ensure it is compliant with the Equality Bill, and promote further research on ageing. [Recommendation 28]***

44 "Part of the assessment process by the MHRA involves ensuring that the target population to be treated once the medicine is licensed has been adequately represented (including age, gender, ethnicity) in the clinical trials submitted in support of the application. There are regulatory guidelines that specify the inclusion of the elderly in clinical trials if they are likely to be included in the population to be treated," Lord Warner in response to PQ, 15/03/04. Analysis of trials protocols submitted to the MHRA shows that in 2006 55% of commercial trials included older people (over 65s, information is not available that subdivides this group). This rose to 58% in 2009. 37% of commercial trials in 2009 only included people from 18 – 64 and 1% only included those over 65.
In 2006, the EMEA reviewed the adequacy of guidance on the elderly regarding medicinal products for human use. It considered a sample of ten product dossiers and found they were in compliance with the International Conference of Harmonisation (ICH) E7 overarching guideline (this includes requirements such as at least 100 patients over 65 and protocol including the >75 age range). For more information see http://www.emea.europa.eu/htms/human/elderly/EMEA_efforts.htm.
It would appear that marketing approvals that specify age limits therefore do so in large part because the treatment is not safe or effective for other age groups, or because insufficient people in an age group were prepared to participate in a trial, or because there was a robust reason for excluding certain age groups.

45 For under representation of older people in clinical trials see 'Including Older People in Clinical Research', McMurdo, *BMJ* 2005.

Conclusion

9.1 When the shadow of age discrimination hangs over a health or social care organisation or is part of a discussion between a health or care professional and a patient, service user or carer, the quality of the service is affected. Patients, service users and their carers have a poor experience and feel they have been unfairly treated.

9.2 The Equality Bill will provide a stimulus for change but the task is not narrowly confined to implementing the letter of the law. Rather the goal is to change the experience of members of the public so that they are not worried that the care and treatment they receive is based on their age but, rather, is based on their individual need and services are delivered in a personal way.

9.3 Organisations and their staff need to recognise that ending age discrimination and promoting age equality is at the heart of the transformation of public services. Our values require it; our system is shaped in a way to enable it; and our recent progress in tackling explicit age discrimination shows we have the capacity to do it.

9.4 The change will result from the actions of the health and social care system, statutory organisations and their partners, and individuals who provide care and treatment. The challenge of transforming the experience of patients and service users requires us to be honest about the nature of current discrimination and open to new ways of working that lead to improvement.

9.5 The evidence we have seen has convinced us that on many occasions people get a good service whatever their age including, where necessary, services tailored to a particular age group. However, it is also clear that this is not always the case. Each instance of age discrimination is a failure that can affect both the health and well-being of the person or group discriminated against and the reputation of our system amongst the people we serve. As well as being wrong in itself, age discrimination is also often a sign of weaknesses in commissioning, quality of care and personalisation and the responsiveness of providers to meet individual needs. Addressing and preventing age discrimination is therefore an important component of achieving the broad strategic aims of delivering high quality health and social care as well as meeting the requirements set out in the Equality Bill.

9.6 While this review has sought to capture the complexity of age discrimination and to produce recommendations that do justice to that complexity, the challenge posed by the ban on age discrimination can be very simply expressed: the health and social care system, along with other services, will not be permitted to treat people less favourably on the basis of age (except where such treatment can be shown to be ‘objectively justified’).

9.7 As the system prepares to implement the age-related provisions of the Bill, including the public sector equality duty as well as the ban on age discrimination, the basic question 'is this less favourable treatment' will need to be asked at all levels of the system and in all localities. It will need to become part of our basic thinking and processes as commissioners and providers of care. The toolkit that has been developed alongside this review provides a practical means of integrating the requirements of the legislation into the processes of the health and social care system.

Annex A: Summary of evidence gathering

The review was announced by the Secretary of State in April 2009. The Department of Health had started work on the age related provisions in the Equality Bill in November 2008 – an advisory group had been established and a number of papers had been commissioned from academic and policy groups.

The approach of the review has been based on the key principles of change management – co-production, subsidiarity, local leadership and alignment. We have also sought to be transparent in our work and so a set of working papers have been made available alongside this report.

The workplan was structured around three parallel workstreams:

1. National Workstream

The national workstream focused on producing a broad analysis of the key issues related to age equality and ending age discrimination in health and social care and testing this at a national level.

Work commissioned and undertaken at a national level included:

a) Establish the National Advisory Group under the chair of John Dixon, Director of Adult Services at West Sussex County Council. The membership of the group is attached.

b) Issue a 'call for evidence' in May. The review received 79 written submissions from a range of respondents – academic bodies, Local Authorities, NHS bodies, third sector organisations, professional associations, Royal Colleges, pharmaceutical companies and one individual.

c) Commission additional reviews of the literature – building on the earlier work commissioned by the Department of Health[46], the Centre for Policy on Ageing have produced five literature review covering costs and benefits of legislation, primary and community health services, secondary health care services, mental health services and social care services. They also hosted a symposium attended by over 40 people on 2 October to discuss the key themes from their work. A summary of the key themes is included in the working papers

46 For the research conducted in advance of the review see http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085763 (*A literature review of the likely costs and benefits of legislation to prohibit age discrimination in health, social care and mental health services and definitions of age discrimination that might be operationalised for measurement,* Centre for Policy on Ageing 2007*;* Cost-*effectiveness analysis and ageism: a review of the theoretical literature,* Edlin et al 2008; *Age Discrimination in Mental Health Services,* Beecham et al 2008; *The costs of addressing age discrimination in social care,* Julien Forder 2008).

d) The Department of Health had commissioned a literature review from the University of Leeds on cost effectiveness analysis and ageism and a summary of the work of the review in this area is included in the working papers. It had also commissioned work from the Personal Social Services Research Unit on costs in mental health and social care.

e) An internal review to identify the key national age-explicit criteria used by the Department of Health and its arms-length bodies, which is summarised in the working papers.

f) Liaison with key national stakeholders: Sir Ian Carruthers OBE and Jan Ormondroyd have met with key national stakeholders across government, from representative organisations other national bodies involved in health and social care, such as the regulators.

g) Presentations to the NHS Operational Board, the National Clinical Directors, the Social Partnership Forum and events for specific audiences, including groups that have been less frequently engaged in the past.

2. The South West Workstream

The regional workstream in the South West has been designed to inform and develop the national analysis with a particular focus on the practical implementation of measures to end age discrimination and promote age equality. It has been structured around the following pieces of work:

a) Establish a Regional Advisory Group: chaired by the Project Director, the Regional Advisory Group has explored the key themes of the review bringing insight from a diverse range of backgrounds from round the South West. The membership is attached.

b) Eleven Local Engagement Events: these have covered every PCT/LA area in the South West plus two events outside the region and included people from a wide range of backgrounds such as

- From local authorities – executive members, directors, commissioning managers, service managers, social workers and corporate performance and equalities managers

- From PCTs – non-executive and executive directors, commissioning managers, GPs, public health professionals, community nurses, public involvement and equalities specialists

- From NHS providers – consultants in care of the elderly medicine and older age psychiatry, nurse and professions allied to medicine consultants and specialists, human resources managers, complaints and PALS managers and specialty managers

- From third sector organisations – managers and officers from campaigning and provider organisations such as local groups representing specific interests and ethnic groups, Help the Aged and Age Concern and Alzheimer's Society

- From the independent sector – managers and nursing staff from residential and home care providers

- Members of the public and their representative groups, including older people's forums, Local Involvement Networks and local campaigning and support groups, such as those working with ethnic minority and disability groups

to explore the local solutions to ending age discrimination. The key themes from the events are summarised in the working papers.

PCT/LA	DATE
Cornwall and IoS	8th October
Plymouth	14th October
Devon and Torbay	21st September
Dorset	6th October
Bournemouth and Poole	10th September
Bristol, N Somerset and South Gloucestershire	28th September
Gloucestershire	24th September
Wiltshire, Swindon and Bath and North East Somerset	1st October
Somerset	13th October
Leicester	5th October
Lewisham	18th September

c) An analytical project with the School of Health and Social Care at the University of West of England looking at indictors to help local analysis of services for potential age discrimination and work on local needs assessment by health and social care in the Joint Strategic Needs Assessment. Both pieces of work are summarised in the working papers.

d) Co-production of the resource pack that will help the NHS and Local Authorities implement the legislation. The NHS and Local Authorities in Dorset, Cornwall and Bristol have supported this work as have a range of third sector organisations across the region. The resource pack is described in more detail in the working papers and has three main components

- An “audit tool” to enable local NHS organisations and Local Authorities to undertake an audit and gap analysis of their status with regards to the implementation of the requirements of the new Equality Bill in relation to age equality and ending age discrimination. The work is being co-ordinated by the National Development Team for Inclusion.

- A good practice guide for the NHS to help commissioners and providers in health care with advice and ideas to address the issues that the local audit will identify and implement the requirements of the Equality Bill. This work is being co-ordinated by a team of consultants led by Ros Levenson with Help the Aged and Age Concern as consulting partners.

- An illustrative practice guide for social care organisations to promote age equality and tackle age discrimination in social work, social care commissioning and service provision. This work was commissioned by the Department of Health from the Social Care Institute for Excellence (SCIE) alongside the review and has linked into the resource pack.

e) Presentations to the Regional Forum on Ageing, the South West NHS Chairs and Chief Executives’ Meeting, Regional Association of Directors of Adult Social Services, SW NHS Medical Directors, SW NHS Nursing Directors, SW Equality and Diversity Leads.

3. The Nation-wide Workstream

The nation-wide workstream has engaged the regions outside the south-west with the national and regional work, providing them with an opportunity to shape the work and provide input on the key themes. It also has enabled a two-way exchange of ideas with the devolved administrations. There has been a National Reference Group with representatives from SHAs, the local NHS, Government Offices and local government through regional ADASS groups.

Membership of the National Advisory Group

Chaired by John Dixon, Deputy Chief Executive and Director of Adults and Children's Services, West Sussex County Council

Andrew Harrop	Age Concern and Help the Aged
Robert Brown	Age Concern and Help the Aged
Charlotte Potter	Age Concern and Help the Aged
Kim Wright	Association of Directors of Adult Social Care and Hackney Council
John England	Association of Directors of Adult Social Care and Leeds City Council
Neil Hunt	Alzheimer's Society
Jane Farrier	Audit Commission
Dr David Oliver	British Geriatrics Society
Dr Finbarr Martin	British Geriatrics Society
Dr Rekha Elaswarapu	Care Quality Commission
Amanda Hutchinson	Care Quality Commission
Gillian Crosby	Centre for Policy on Ageing
Carla Garnelas	Children's Rights Alliance England
Andrew Young	Council for Healthcare Regulatory Excellence
Sheila Wild	Equality and Human Rights Commission
Nony Ardill	Equality and Human Rights Commission
Alessandra Peck	Equality and Human Rights Commission
Elaine Bromberg	General Medical Council
Gill Rendall	Government Equalities Office
Michael Guthrie	Health Professions Council
Umar Zamman	Leicestershire County & Rutland PCT
Alyson Morley	Local Government Association
Paul Farmer	Mind
Prof. Peter Littlejohns	National Institute for Health and Clinical Excellence (NICE)
Nick Doyle	NICE
Pat Healy	National Pensioners Convention
Mark Platt	National Voices
Jo Webber	NHS Confederation

Lorene Read	NHS Confederation and Weston Area Health Trust
Dr Yvonne Doyle	NHS South East Coast
Natalie Salmon	Nursing and Midwifery Council
Dr Maureen Baker	Royal College of GPs
Dr David Anderson	Royal College of Psychiatrists
Annie Stevenson	Social Care Institute for Excellence
Barbara Webster	South Birmingham PCT
Carl Petrokovsky	South East Public Health Group
Ruth Corden	West Sussex County Council
Colin Derrig	Unison
Andrew Webster	Independent social care consultant and national advisor to the review
Judith Saville	Secretary, Project Administrator

Membership of the Regional Advisory Group

Chaired by Richard Gleave, Project Director

Lorene Reed	CE – Weston Area Health Trust
Jan Stubbings	CE – NHS Gloucestershire
Anthony Farnsworth	CE – Torbay Care Trust
Angela Schofield	Chair – NHS Bournemouth and Poole
Judith Geddes	Director Adult Services – Bournemouth
Paul Dunn	CE Equalities SW
Chris Plaister	Vice Chair – South West Seniors Network
Faith Davey	Regional Director – Age Concern/Help the Aged
Tarun Solanki	Regional Secretary British Geriatric Society and CoE Physician at Taunton
Candy Baker	Patient representative
Vicki Sheen	Head of Physiotherapy, Torbay Care Trust
Jim Grant	Divisional Manager, Royal United Hospital Bath
Matthew Riddle	Executive Member for Adult Social Care and Housing, South Gloucestershire Council
Nigel Ashton	Leader and Executive Member for Adult Social Care, North Somerset Council

Roger Bullock	Clinical Director for Older Age Psychiatry, Avon and Wiltshire Partnership Trust
Nye Harries	Regional Change Agent – Older People, DH
Philip Johnson	Assistant Director – Economy, Growth and Regeneration GOSW
David Philips	Director of Public Health, NHS Dorset
Ian Biggs	Regional Director – Care Quality Commission
Karen Tanner	Associate Director of Patient Care – NHS South West
Shamala Govindasamy	Senior Programme Lead SW Councils
Robin Cowen	Independent consultant and regional advisor on social care
Judith Saville	Secretary, Project Administrator

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