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CPA briefings

A REVIEW OF AGE DISCRIMINATION IN PRIMARY AND COMMUNITY HEALTH CARE, SECONDARY HEALTH CARE, MENTAL HEALTH CARE AND SOCIAL CARE SERVICES IN THE UNITED KINGDOM

THE CENTRE FOR POLICY ON AGEING (CPA) carried out a series of five literature based reviews in 2007 and 2009, commissioned by the Department of Health, to look for evidence of age discrimination in health and social care services in the United Kingdom. The reviews looked at the costs and benefits of age discrimination legislation and at evidence of discrimination in primary and community health care, secondary health care, mental health care and social care. The CPA reviews support the Department of Health's activities to root out age discrimination in the context of the European Commission Draft Directive (July 2008) – COM (2008) 426 and the introduction in the UK Parliament of the Equality Bill (April 2009) and related secondary legislation that will set out details of the new age discrimination ban in the provision of goods and services.

The body of work produced by CPA informed the national review on age discrimination, which brought together evidence from a range of sources to examine the extent to which health and social care services are differentiated by age, where people may receive less favourable treatment because of age, and where this may be unlawful and therefore constitute discrimination under the Equality Bill, culminating in a report to the Secretary of State for Health in October 2009.[1] Key principles underpinning the work around age equality in health and social care include:

- unjustifiable age discrimination and unfair treatment based on age have no place in a fair society, which values all its members;
- personalisation means that meeting individuals' needs for health and social care should be based on their individual condition and circumstances, not assumptions about their age;
- services should be differentiated by age only where this is beneficial and therefore objectively justifiable (see explanation below);

[1] 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, October 2009. http://www.cpa.org.uk/cpa/achieving_age_equality_in_health_and_social_care.pdf

- services should demonstrate value and beneficial outcomes for all people in the use of public funds.

The Equality Bill

The Equality Bill creates a single public sector equality duty, covering eight protected characteristics: age, disability, gender reassignment, pregnancy or maternity, race, religion or belief, sex, and sexual orientation. It establishes that discrimination is about relative rather than absolute standards. 'Discrimination law is about a person's treatment relative to that of a comparator (except pregnancy and maternity) including a hypothetical comparator (except equal pay), not about absolute standards.' Direct discrimination is treating someone *less favourably because of a protected characteristic*. This does not have to be the victim's own characteristic: association and perception are also covered. Indirect discrimination is applying to someone a provision, criterion or practice which puts them, and persons with whom they share a protected characteristic, *at a particular disadvantage*. When assessing evidence of discrimination it is important to be clear that disadvantageous discrimination that would otherwise be indirect discrimination (for any protected characteristic), and less favourable treatment that would otherwise be direct discrimination (for age only) is not discrimination if the person applying it can show it to be a proportionate means of achieving a legitimate aim (also referred to as 'objective justification').

Ageism and age discrimination

The CPA reviews distinguished between *ageism*, a term first used in the late 1960s to describe an unjustifiable prejudicial attitude of mind towards older people, and *age discrimination*, discriminatory actions, made purely on the basis of age that can be observed and, perhaps, measured. Age discrimination can occur in a variety of ways. *Direct* age discrimination treats two individuals with similar needs differently purely on the basis of their age. *Indirect* age discrimination treats people of all ages the same, not recognising the greater needs of particular age groups so those age groups are disadvantaged. *Institutional* age discrimination is age discrimination written into policies and practice. *Individual* age discrimination is discriminatory action taken by individuals as a result of their own personal ageist attitudes. *Overt* age discrimination is age discrimination that is open and observable. *Covert* age discrimination is hidden and possibly even subconscious. Institutional age discrimination is likely to be overt. Individual age discrimination is likely to be covert.

Age differentiated behaviour is a well thought out and justifiable difference in treatment by age based on a well developed understanding of age differences.

Age discrimination in policy

The audit by the Healthcare Commission (2006) found that explicit age discrimination in policy has declined since the National Service Framework for Older People was introduced in 2001.

The key exceptions are age cut-offs in screening programmes by invitation, the age based organisation and provision of mental health services, the age based organisation and provision of social care services and, arguably, the National Institute of Health and Clinical Excellence's (NICE) use of the Quality Adjusted Life Year (QALY) in assessing the overall relative cost effectiveness of treatments that are only or mainly of benefit to older people. Although not strictly part of health and social care, related benefit payments such as

Attendance Allowance, Disability Living Allowance and Independent Living Funds have age-based cut-offs in their application which may conflict with age discrimination legislation.

Sreening programmes

One of the most explicit forms of age discrimination in healthcare in the NHS is the upper age limit on some screening programmes by invitation, not indicated by disease prevalence or other clinical indicator. Upper age limits currently exist of 69 for breast and bowel cancer screening and 64 for cervical screening by routine invitation.

Women from 50-70 are routinely invited to breast screening; once women reach the upper age limit for routine invitations for breast screening, they are encouraged to make their own appointment. The research shows that breast and cervical screening offer the most benefit and that extending breast screening to the age of 74 would be more effective than cervical screening at any age. It also indicated that cervical screening policy should be extended to the age of 69 because more lives are lost to cervical cancer among women in their 70s than among women under 30. Many more older women attend screening following an invitation than had previously self-referred and cancer detection rate is higher in the 65-70 group than in the 60-64 group.

The UK's national bowel screening programme has an age span of 60-69 although there are plans to extend this to 75 at the end of 2010; people outside the upper age limit have to be highly proactive and request a screening kit by telephone. There is no clear evidential base for the upper age limit in the bowel screening programme.

The new UK vascular screening programme for 40-74 year olds was launched in April 2009. The upper age limit has been capped at 74, which excludes a large number of people who may benefit as vascular problems intensify with age. To prevent stroke, it is important to ensure that hypertension is also controlled in people over 75, the age group which has the most strokes.

Quality Adjusted Life Years (QALY)

There is divided opinion over whether the QALY, the primary measure by which the National Institute for Health and Clinical Excellence (NICE) assesses the cost effectiveness of procedures and treatments, is inherently age discriminatory. There is a strong suspicion that, no matter how it is packaged, the use of Quality Adjusted Life Years to assess the relative cost effectiveness of treatments and procedures will discriminate against those procedures and treatments, for example for Alzheimer's disease, osteoarthritis, osteoporosis or macular degeneration, that are mainly beneficial to older people with few remaining years. Frail, older people with co morbidities may be particularly disadvantaged as successful treatment of one aspect of ill health will be less effective in terms of overall health benefit.

It is however argued that, on the contrary, treatments provided on a pay-as-you-go basis, without large up-front costs, have the same marginal cost / benefit trade-offs at any age.

Organisation of mental health and social care services

There is widespread variation in the way in which mental health services for older people are organised but, in most areas there are separate adult and older people's services with, in many areas, transfer between the services at age 65. One third of authorities do not have transition protocols in place and levels of provision are less good in older people's mental

health services for 'graduates' who transfer between services with a continuing mental health problem.

> The exception to this decline in explicit discrimination is mental health services where the organisational division between mental health services for adults of working age and older people has resulted in the development of an unfair system, as the range of services available differs for each of these groups. For example out-of-hours services for psychiatric advice and crisis management for older people are not as developed as those for adults of working age. Older people who have made the transition between these services when they reached 65 have said that there were noticeable differences in the quality and range of services available. [2]

The mental health needs of older people may be sufficiently different from those of adults to justify the provision of specialists older people's mental health services but, while there is some evidence of the success of these services, they have not, in the past, achieved the necessary level of commissioning priority or service provision to provide a non age discriminatory service.

There is explicit direct age discrimination in social care provision resulting from the division of social care services into adult and older people's services (from age 65) with poorer services and reduced funding for older people. Transition between services is usually triggered by age rather than need. Concepts of independence and social care are often interpreted differently and more restrictively for older people than for other adult client groups. Younger adults with disabilities are supported to achieve greater independence and to exercise more choice than older people.

Age discrimination in practice

Direct

Although not explicit and overt, there is widespread evidence of the unjustified differential treatment of older people as a group in both primary and secondary healthcare. The discrimination is mainly covert and results from the cumulative effect of ageist attitudes by individual healthcare workers. Some age discrimination is direct discrimination and manifests itself, for example, in lower rates of referral and more late referrals of older people to specialist care by General Practitioners (GPs), the lower proportion of quality of care indicators met in primary care for geriatric conditions compared with general medical conditions, lower application rates of primary and secondary prevention for older people, lower rates of appropriate surgical intervention for older people and lower rates of appropriate diagnosis and treatment for heart disease, cancer and transient ischaemic attack and stroke for older people, even after issues of frailty and comorbidity have been taken into account.

GPs have been widely criticised for their reluctance to diagnose dementia and for delays in the diagnosis of both dementia and depression in older people. GP training and the

[2] Healthcare Commission, Audit Commission and Commission for Social Care Inspection (2006) *Living well in later life: a review of progress against the National Service Framework for Older People*, London: Healthcare Commission

screening tools used in general practice may be insufficient to meet older people's mental health needs.

Indirect

Much age discrimination experienced by older people in health and social care is, however, indirect, either through the inadequate provision of services mainly used by older people or the equal application of policies to the disadvantage of older people with greater needs. Discrimination is implicit in a general lack of priority for and under investment in community services that benefit older people, such as chiropody, integrated falls services, incontinence services and audiology services. There are barriers to older people accessing rehabilitation services and dental services; older people have hearing and vision conditions that are not identified but could be treated; and there can be long waiting times to access aids that would significantly improve quality of life. Palliative care and pain management are identified as being poorly provided for within the community and there is evidence of unmet need.

Hospital discharge policies, equally applied, result in higher rates of emergency readmission within 28 days of discharge for those aged 75+ and the gap is widening. The cut back in GP home visit consultations from 22% in 1971 to 4% in 2006 and the recent reorganisation of out-of -hours services affect older people disproportionately. The late diagnosis and under-diagnosis of dementia, with up to one half of cases going unrecognised and poor quality foot-care services with 58% of older people in need of foot care services having to make private provision are likely indicators of indirect age discrimination in these areas.

Institutional ageism leads to an expectation by social care service providers that older people, i.e. anyone over 65 referred to older people's services, will accept a different and inferior quality of life compared to the rest of the population. This is partly due to lack of resources and a legacy of historical ageism whereby previous patterns of service become the 'norm'. There is clear evidence that older people have aspirations to lead a good life based on their own ideas of what constitutes a life worth living.

In social care there is evidence that service users' emotional and other broad quality of life needs are not being met under increasingly strict eligibility criteria which attend to direct physical needs only. This is likely to have a disproportionate affect on older people with mobility and sensory impairments, living alone, and who may not have any access to support to meet their psychological, emotional, social and spiritual needs.

There is widespread anecdotal and review evidence of the under-provision of mental health services for older people. Older people's mental health services have fewer psychiatrists, psychologists, psychotherapists, therapists and social workers per case than adult mental health services. Less money is spent on older individuals after taking all other factors into account.

Dementia is almost exclusively a condition of older age so the under-provision of appropriate treatment may be indirect age discrimination. Dementia is not directly comparable with any other condition but there are indications of inadequate treatment. Only one third of dementia sufferers are formally diagnosed at any time in their illness and late diagnosis is common. The United Kingdom compares badly with most other European countries in the percentage of people with Alzheimer's disease treated with anti-dementia drugs.

Although it is agreed, at national level, by professional bodies and the government, that health, mental health and social care services should be organised and provided on the

basis of need rather than age, there is widespread variation in the way services are organised and applied at a local level. Particularly, in mental health services and social care, there is much variation in the degree of age discrimination to be found in the application of policies in different localities. For example, the way local authorities are using eligibility criteria to ration services and allocate limited resources indirectly discriminates against older people. Low level support has become equated with less effective or worthwhile support, but for older people it can be particularly important in maintaining independence, dignity and control of their lives within their own home.

Ageist attitudes

Individual ageist attitudes underpin much of the age discrimination observable in health and social care. There is evidence that the ageist attitudes held by health and social care staff are pervasive and likely to reflect ageist attitudes in society as a whole. Practitioners may have low expectations of what services and interventions can achieve for older people and make assumptions about their needs and capabilities. In health care ageist attitudes can be a barrier to implementing evidence-based guidelines in treating older people and may lead to a general failure to take problems that are treatable seriously. Although legislation can provide a marker, ageism in health and social care has to be addressed through a longer term programme of intervention in education and training. In addition, health care professionals ought to be much more aware of the physiology and needs of the older patient. Old age psychiatry is under represented in general psychiatric training. Good quality placements and teaching during training have been identified as key factors in attracting clinical psychologists to work with older people.

Clinical trials and research

To avoid the complications of comorbidity, older people have often been excluded from clinical trials. The situation is improving but there is still a large knock-on effect in healthcare, with approved drugs not having been tested on older people, so doctors have to either not prescribe or prescribe 'off label'. The continued under-representation of older people in clinical trials is a clear form of age discrimination outside the NHS which has a knock-on effect on available treatments for the older patient inside the NHS. Changes to the regulatory frameworks controlling pharmaceutical and medical device licensing might bring pressure for further improvement.

Integrated care

A multidisciplinary approach to care of older people with complex needs is not well developed within health settings, across health and social care and other mainstream services. The current structure of the NHS, with its focus on 'specialisms', creates barriers to treating people with multiple conditions cutting across medical boundaries and care settings. There is evidence that multidisciplinary teams can achieve better outcomes for people with multiple pathologies and functional problems.

Care homes

Older people needing support are more likely to enter care homes without a comprehensive assessment and opportunity for rehabilitation, compared to younger people requiring support. There is evidence that older people living in care homes have difficulty accessing the services of a GP and other community health care services.

Ageist attitudes and the dominance of a professional perspective can lead to assumptions about how older people should lead their lives in care homes with an emphasis on managing dependency and decline. Quality of care, interconnected with quality of life issues, includes promoting and enhancing the wellbeing of people, attending to their emotional, psychological and social needs as well as their physical needs.

The mental health care of older people in residential care leaves room for improvement. About 60% of care home residents suffer from dementia and around 27% suffer from depression. Despite this only 8% of care home staff have any training in psychological or psychiatric care and only 12% of care homes have direct access to psychiatric services. There is evidence of the widespread inappropriate use, in care homes, of anti-psychotic drugs to sedate older people with dementia.

Cost/benefit analysis of legislation to ban discrimination in health and social care

Finally, although it has been estimated that to bring older peoples services up to the level of the best, for mental health care alone, would cost £2 billion per year, national health and social care budgets are largely determined by external factors and, although the elimination of age discrimination may result in a redistribution of funds within health and social care, evidence from other countries indicates that the introduction of age discrimination legislation has little or no long-term effect on the total budgets.

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The five reviews collate a wealth of evidence of some direct but mostly indirect, covert discrimination affecting the quality and range of services available to older people. The individual reviews can be accessed from the CPA website via the link below:

- Ageism and age discrimination in secondary health care in the United Kingdom
- Ageism and age discrimination in primary and community health care in the United Kingdom
- Ageism and age discrimination in mental health care in the United Kingdom
- Ageism and age discrimination in social care in the United Kingdom
- 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

http://www.cpa.org.uk/information/reviews/reviews.html

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For further details of the CPA's work, contact the Centre's Director, Gillian Crosby, email gcrosby@cpa.org.uk

Access government policy documents on ageing issues via CPA's website www.cpa.org.uk/cpa/policies_on_ageing.html

Selected reading lists are available to download from CPA's website www.cpa.org.uk/information/readings/readings.html

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