

Ageism and age discrimination in social care in the United Kingdom

A review from the literature

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Department of Health

carried out by the
Centre for Policy on Ageing



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Contents

1	Introduction	5
	1.1 Scope of review of adult social care	5
	1.2 Context of review of adult social care	5
	1.3 Classification of evidence	6
2.	Government policies to support older people	7
3	Ageism and age discrimination	10
	3.1 Definitions	10
	3.2 Equality Bill	11
	3.3 Identifying age discrimination	12
4	Ageing population and disability	13
5	Ageist attitudes	14
	5.1 Education and training	15
6	Adult social care services	15
	6.1 Services for older people	17
7	Expectations and aspirations	19
	7.1 Service providers	19
	7.2 Aspirations of older people	20
	7.3 Hearing the voices of older people	21
8	Assessment and care management	23
	8.1 Focus of assessment	24
	8.2 Quality of assessment	25
9	Eligibility criteria for accessing adult social care	27
10	Age related benefits and grants	29
11	Allocation of resources and funding	30
	11.1 Social care budget	30
	11.2 Allocation of resources within adult social care	31
	13.3 Funding for home care and residential care	33
12	Charging policies	37
	12.1 Non-residential services	37
	12.2 Residential services	37
13	Quality of residential care	38
14	Extra care housing	40

15	End of life care	41
16	Older people with learning disabilities	42
17	Older prisoners	44
19	Conclusion	44
	19.1 Age discrimination in systems and structures	45
	19.2 Age discrimination in policy and practice	46
	19.3 Age discrimination in resources and funding	47
	19.4 Recommendation for further research	47
20	References	48

Appendix 1 – Methods

Appendix 2 – Bibliography

This review is one of four reviews of ageism and age discrimination in health and social care available from <http://www.cpa.org.uk/reviews>

1. Introduction

1.1. Scope of review of adult social care

The Department of Health (DH) commissioned the Centre for Policy on Ageing (CPA) to undertake a review from the literature to determine whether older people in the United Kingdom are treated less favourably than younger users of social care in the way resources are allocated, needs are assessed, care is planned and services are delivered. Younger users are defined, in this context, as working age adults, i.e. 18-64 years of age and older people are defined as over 65 years of age. This study looks at all aspects of the potential for ageism and age discrimination in adult social care including institutional and individual ageism and age discrimination; quality and level of services; direct and indirect discrimination; differential levels of funding; attitudes of professional staff; and evidence reflected in the attitudes and views of service users.

The DH commissioned CPA to undertake separate reviews from the literature to provide evidence of ageism and age discrimination in primary and community health care, secondary health care and mental health services. The four reviews are rapid semi systematic literature reviews and not systematic reviews. Each review was conducted over a period of ten weeks. While it is acknowledged that discrimination related to age based assumptions can be directed at people of any age, this report on adult social care, and the CPA reviews on health care, focus primarily on the experiences of older people. Issues around multiple discrimination, gender and minority ethnic groups are not singled out for special attention but are discussed within individual studies.

1.2. Context of review of adult social care

The evidence from this study of adult social care will 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. It informed the national age discrimination review on health and adult social care led from the South West region by Sir Ian Carruthers, Chief Executive of the South West Strategic Health Authority, and Jan Ormondroyd, Chief Executive of Bristol City Council. The national review obtained 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. The report of the national review (Carruthers and Ormondroyd 2009) includes recommendations on the timing of implementation of the ban and on those areas of age-based differentiation that should be maintained under the new law.

The national age discrimination review is informed by a number of key principles including:

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

1.3. Classification of evidence

The CPA review of adult social care has considered information from organisations, practitioners, the policy community, research, and user and carer sources to uncover possible evidence of age discrimination in social care. A systematic review of age discrimination in social care has not been located. Although organisations representing the interests of older people have regularly produced reports describing incidents of unfair treatment of older people age discrimination has only fairly recently (compared for instance to race, gender and disability) achieved a higher national profile as the population ages and is the least well researched (Levenson 2003, study; Abrams et al 2009, review). The systematic gathering of evidence of age discrimination has been limited and relates mainly to employment practices and the job market (Ward and Bytheway 2008, review; Macnicol 2006, review). 'One of the key issues is people's unwillingness to acknowledge or to take seriously the nature of age discrimination' (Abrams et al 2009, review).

This review of ageism and age discrimination in social care has been constrained by the studies that have been carried out to date, the ability to search and find evidence in such a disparate and extensive literature within the given time frame and obviously the varied approach of each study. Although search processes have been rigorous, inevitably some relevant literature may have been overlooked. (See Appendix 1 for information on the methodology.)

To make it easier to assess the nature and weight of the evidence presented in this report we have split the sources of the evidence into a small number of simple categories. Category labels have been added to the reference citations in the body of the text to provide an at-a-glance first indication of the weight of the evidence.

Large survey
Survey

Sample survey of 800+ from a large population
Sample survey of 120-800 from a large population or 50%+ from a small population. We will use the generic term *survey* to

	include retrospective case audits.
Small survey	Sample survey of less than 120 from a large population or less than 50% of a small population
Group study	Focus group, panel or equivalent study
Study	Individual research project, observational study or analysis not carried out as a group study or survey
Opinion	Opinion of a respected authority, editorial etc.
Systematic review	Systematic review, with or without meta analysis
Review	Literature and other reviews not structured as a 'systematic review'
Policy document	Government or professional overview
Campaign document	Document to promote a particular point of view
Guide	Guide, information pack or toolkit

2. Government policies to support older people

The Labour government is supporting a continuing process of developmental work comprising research, strategies and initiatives that are designed to improve outcomes for older people and act as levers for tackling inequalities in services. Activities include the National Service Framework for Older People (NSFOP) (DH 2001); the cross government strategies on ageing - Opportunity Age (2005) and Building a Society for All Ages (2009); the Dignity in Care campaign (2006); Public Service Agreement 17 – to Tackle Poverty and Promote Greater Independence and Well-being in Later Life; the End of Life Care strategy (2008); and the National Dementia Strategy (2009).

Standard 1 of the NSFOP is 'Rooting out age discrimination' to counter infringement of dignity and unfair discrimination in older people's access to care. It states:

NHS services will be provided, regardless of age, on the basis of clinical need alone. Social care services will not use age in their eligibility criteria or policies, to restrict access to available services.

While the Department of Health acknowledged discrimination can be positive, within the NSFOP it used it in the negative sense relating specifically to 'action which adversely affects the older person because of their chronological age alone' (DH 2001, policy document) (see section 3.2).

In developing the NSFOP, the DH suggested that 'Instances of adverse discrimination have usually been inadvertent, a result of the survival of old systems and practices that have failed to keep pace with changing attitudes or advances in the capacity of professionals to intervene successfully.' It used as examples evidence that councils can discriminate against older people where they apply commissioning strategies that are not sufficiently flexible to take account of individual needs; eligibility criteria for non-residential services mean older people have had to demonstrate higher needs to qualify for services compared with younger adults; considerable variation across the

country in the range of services available to older people and their families or carers; older people from black and minority ethnic groups can be particularly disadvantaged.

In an interim review of discrimination (DH 2002, study), an audit of council social care policies identified areas that could be age discriminatory in effect: social care eligibility criteria; funding of residential care; funding levels for home care support; charging policies for domiciliary care; housing policy; access to day care. The availability and access to services by older people is affected by implicit or unintended discriminatory practices. Concerns relating to social care include: access to services in the community; access to rehabilitation; misdiagnosis of abuse; levels of home care available.

Independence, Well-being and Choice: our vision for the future of social care for adults in England (DH 2005), *Our Health, Our Care, Our Say: a new direction for community services* (DH 2006), and the *National Service Framework for Long Term Conditions* (DH 2005) set out the government's vision for services to meet people's aspiration for greater control over their lives and to be more responsive to individual needs. The focus is both on 'personalisation' – so that every person who receives support has choice and control over that support in all care settings – and on early intervention and prevention. *Putting People First* (HM Government 2007) establishes a collaborative approach to transform adult social care. Local authorities, in partnership with a wide range of organisations and agencies, are challenged to ensure there is personalised support for people with multiple and complex needs, for people to maintain their independence and for people with emerging needs. The mechanisms to achieve this include individual budgets, joint commissioning between health and social care, and an increase in care outside hospitals. It sets out 'a vision for adult social care of services that are seamless, proactive and person centred' (Clough et al 2007).

The Health Prevention Package (PP) for Older People, launched by DH within the government ageing strategy *Building a Society for All Ages* (July 2009), prioritises better preventive care for older people. It aims to promote and encourage uptake of comprehensive health and social care services for older people to cover falls prevention, footcare services, audiology services and existing NHS entitlements such as free eye tests. A refresh of intermediate care guidance is tackling the issue of inappropriate discharge from acute care into long term residential care without giving people the opportunity to benefit from recuperation and rehabilitation, and allowing for a comprehensive assessment of needs in a supportive environment.

The most recent Green Paper on social care, *Shaping the Future of Care Together* (DH 2009) reiterates previous objectives of prevention services, joined up service, and personalised care and support but also proposes a National Care Service with national assessment criteria, information and

advice. However, the Green Paper's primary focus is on funding a new system of social care to support the care of older people, with the suggestion that older people should bear most of the cost themselves. Voluntary sector organisations working on behalf of younger adults have criticised the lack of a comprehensive approach, 'The government's green paper was focused on the elderly. We all know that's a big issue, but equally there's a whole question of how the social care system looks after people with learning disabilities' - Heather Honour, director of the Learning Disability Coalition (*GuardianSociety* 2009, opinion). Niall Dickson, chief executive of the King's Fund, commented 'It suggests with some justification that different approaches can be taken for different groups but it does raise issues of age discrimination and questions over the affordability of a free system for those of working age that does not impact on current benefits' (Dickson 2009, opinion). The government launched the Big Care Debate (ended November 2009) (<http://careandsupport.direct.gov.uk>) to engage the general public in the reform of adult care and support in England.

Interim reports evaluating the Partnerships for Older People projects (POPPs) have provided some evidence that care initiatives that focus on early interventions can have a positive impact on people's health. Examples of pilot schemes include home from hospital, which offers flexible, short-term person-centred practical assistance and support (not personal care) to older people leaving hospital, handyperson schemes, falls prevention schemes, and projects to improving the health and wellbeing of carers by supporting carers in their role with older people. The underlying aim of the 29 pilot sites is to create a sustainable shift in resources and culture away from the focus on institutional and hospital-based crisis care toward earlier and better targeted interventions for older people within community settings. 'In the longer term, the findings from the NE will contribute to the evidence on effectiveness of initiatives aimed at promoting independence, prevention and early intervention' (Windle et al 2008, study).

Joint Strategic Needs Assessment (JSNA), introduced in 2008, requires primary care trusts and local authorities to jointly assess the needs of their local population. In a *Report on Disability Equality* (2008, policy document) the DH states that commissioners are required to consider services for older adults as an integral element of their overall service provision, noting that they constitute the majority of disabled people within the community. Services include access to occupational therapy to help achieve maximum autonomy and independence and access to community equipment as a gateway to independent living.

3. Ageism and age discrimination

3.1. Definitions

Robert Butler (1969) introduced the term 'ageism' which he described as having three distinguishable but interconnected aspects (1) prejudicial attitudes towards older people, old age and the ageing process, which includes attitudes held by older adults themselves; (2) discriminatory practices against older people; and (3) institutional practices and policies that perpetuate stereotypes about older adults, reduce their opportunity for life satisfaction and undermine their personal dignity (Nelson 2002, review).

'Ageism is a set of beliefs ... relating to the ageing process. Ageism generates and reinforces a fear and denigration of the ageing process, and stereotyping presumptions regarding competence and the need for protection. In particular, ageism legitimates the use of chronological age to mark out classes of people who are systematically denied resources and opportunities that others enjoy, and who suffer the consequences of such denigration, ranging from well-meaning patronage to unambiguous vilification' (Bytheway and Johnson 1990 in Bytheway 1995)

Prejudice refers to an attitude of mind which may lead to discrimination, while discrimination focuses on behaviour with outcomes that may be measured, assessed and compared.

'Ageism is used to describe stereotypes and prejudices held about older people on the grounds of their age. Age discrimination is used to describe behaviour where older people are treated unequally (directly or indirectly) on grounds of their age' (Ray, Sharp and Abrams 2006). Ray et al identify three different types of discrimination:

- under representative – passive/indirect discrimination by omission
- positive/protective – special treatment to benefit group
- negative/overtly harmful – direct discrimination.

'Ageism is broader than age discrimination. It refers to deeply rooted negative beliefs about older people and the ageing process, which may then give rise to age discrimination. Such beliefs are socially created and reinforced, embedded as they are in functions, institutions, rules and everyday social life (Hewstone 1989, in McGlone and Fitzgerald 2005).

Essed (1991) has developed a theoretical account of everyday discrimination relating to racism. It sets out an argument for the scrutiny of familiar and mundane encounters, rather than exceptional experiences where evidence of discrimination appears indisputable. Essed concludes that systemic racism is reproduced through routine and taken-for-granted practices and procedures in everyday

life, and that is often hard to pinpoint and thus to challenge (Ward and Bytheway 2008). Drawing on Essed's work, Bytheway et al (2007) have developed a definition of everyday ageism:

'Everyday ageism does not exist as single events but as a complex of cumulative practices. Specific instances acquire meaning only in relation to the accumulating total of other experiences of everyday ageism. It involves ageist practices that infiltrate everyday life and are part of what is popularly seen as "normal".'

Some age related practices are based on evidence of actual age related changes that may require differential treatment.

'Ageist behaviour grows out of stereotypes, prejudices and stigmatization. Age-differentiated behaviours are, however, an appropriate function of the age of the target person, based on an understanding of development and thoughtful recognition of age differences' (Hagestad and Uhlenberg 2005).

Distinguishing between age differential and ageist behaviour can be difficult. 'In evaluating whether behaviour is age differentiated or ageist important considerations include the assumed and actual attributes of the older adult recipient of differential behaviour, including their age. ... In many cases differential treatment of older adults reflects negative and unfounded assumptions about their competence' (Nelson 2002, review).

Age discrimination may be direct or indirect in form. Direct age discrimination will occur if people with comparable needs are treated differently or denied access to services purely on the basis of their age. Indirect age discrimination will occur when people are 'treated differently or denied access to services because of a factor other than chronological age, but where that factor may particularly affect older people or where older people may be disproportionately affected' (Levenson 2003).

Ageism or age discrimination that follows directly from the policies, structures and systems is described as institutional. Institutional age discrimination may occur in policy at the political, national or overall level (societal) or at the level of individual institutions (systemic) (Levenson 2003). Institutional or societal /systemic age discrimination includes the imposition of explicit age limits for the provision of services or access to facilities.

3.2. 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') (national age discrimination review health and social care 2009).

3.3. Identifying age discrimination

The Department of Health has developed benchmarking tools to measure and monitor age discrimination in social care, acute hospital and primary care. The DH benchmarking tool for social care (DH 2002) compares services and assessments for different age groups across different local authorities by comparing the ratios of the rates of assessment, and of service provision, for older and younger adults. It also looks at ratios between advanced old age and earlier older. Age discrimination is a possible factor if there are differences in local authority activity for a given amount of need across age groups. However, there may be other local reasons for variations in activity. As Levenson (2003, study) notes there are many factors that make it difficult to identify discrimination including the subtle nature of discrimination, difficulty of assessing whether a decision made by professionals is evidence based, innate ageism of practitioners, older people accepting discriminatory practices as the 'norm', and shortcomings in services that may not be related to age discrimination but are an issue of quality for all groups.

Summary

Discrimination law is about a person's treatment relative to that of a comparator not about absolute standards. In the context of age discrimination, direct discrimination occurs if a person is treated less favourably because of their age. Indirect discrimination occurs if a provision, criterion or practice is applied which puts a person, and others who share a protected characteristic, i.e. age, at a particular disadvantage. It is not considered discrimination if a particular policy or practice applied can be shown to be a proportionate means of achieving a legitimate aim (known as objective justification).

4. Ageing population and disability

Over a third of the total population in the UK, 21 million, are over 50 years of age; nearly 10 million are aged over 65; over 1.3 million are aged 85 and over. About 3.7 million older people live alone (ONS 2009). Older women outnumber older men, with life expectancy at birth in the UK being 77.3 years for men and 81.5 years (ONS 2008). The majority of older people with disabilities are women. Sixty-nine per cent of people aged 85 and over, 56% of those aged 75-85 and 40% of those aged 65-74 in the UK have a disability or limiting long standing illness (DWP 2009). The most prevalent difficulties for older people are those of mobility and sensory impairments (hearing and sight).

The ability or difficulty experienced in performing Activities of Daily Living (ADLs) are widely used as a measure of disability for older people covering personal care such as being able to bathe, dress, mobility and toileting. Instrumental Activities of Daily Living (IADL) relate to domestic tasks such as shopping, cooking and housework, and in some cases using the telephone and managing money. Many different scales have been developed to measure ADLs and have been used in surveys, reflecting different approaches to defining and measuring disability (Jagger et al 2009, study). They share a focus on risk and deficit rather than aspirations and desired outcomes (CSCI 2008, study).

The term 'older people' covers a hugely diverse population from the young old to very old. The National Service Framework for Older People (DH 2001) identifies three groups of older people that may require different types of care:

- **Entering old age** This is a socially-constructed definition of old age, which, according to different interpretations, includes people as young as 50, or from the official retirement ages of 60 for women and 65 for men. These people are active and independent and many remain so into late old age.
- **Transitional phase** This group of older people are in transition between healthy, active life and frailty. This transition often occurs in the seventh or eighth decades but can occur at any stage of older age.
- **Frail older people** These people are vulnerable as a result of health problems such as stroke or dementia, social care needs or a combination of both. Frailty is often experienced only in late old age.

Summary

There are an increasing number of people living into older age who require support to live their lives as a result of disabilities and ill health that restrict their ability to do everything for themselves. Older people should not be viewed as a 'single group' as they are a heterogeneous population with varying needs and resources, although they share experiences associated with ageing. Tools commonly used to measure disability focus on risk and deficit.

5. Ageist attitudes

There is an extensive body of research that indicates ageist attitudes are common in health and social care professionals. The two main reasons given are that professionals are part of a society that constantly demonstrates ageist attitudes and that professionals would therefore be subject to ageist messages and discourses; the other is that for some professionals 'older people represent obstacles to successful practice'. Older people who are frail or have multiple conditions that require complex and long term responses do not fit into the performance indicators of many institutions and organisations (Reed et al 2004, review). Practitioners may not recognise ageist attitudes in themselves. Levy (2001) argued that 'every person who has internalised the age stereotypes of their culture is likely to engage in implicit ageism, and it is for this reason that much ageism is hidden' (referenced in Adams et al 2006).

Billings (2003, group study) undertook a focus group study of 'staff perceptions of ageist practice in the clinical setting' covering both acute and community sectors. There was a consensus that older people were more likely to experience insensitive treatment such as excluding them from conversations, shouting at them and being patronising. 'The general issue of communicating inappropriately to them was a common experience across all groups.' Assumptions were also made about the needs and capabilities of older people that were perceived as 'small but significant examples of ageist practice'.

In a survey of health and social care managers (Roberts et al 2002, survey), many believed that ageism was endemic and affected the services provided to older people.

'[Professionals] don't do enough of assessing need, they see the age first'

(Joint commissioning manager, health authority/social services)

The convention continues of seeing older people as 'vulnerable' and needing protection, as problematic and burdensome, a group denied the ordinary things in life because of the process of ageing, although new developments are beginning to move towards a more holistic view of older people's lives (JRF 2004, study).

Townsend (2006, review) argues that during the final decades of the 20th century, older people were perceived and treated, according to accumulating research evidence, as more dependent than they really were or needed to be. This had been fostered by the emerging institutions of retirement, income maintenance, and residential and domiciliary care leading to what he terms 'structured dependency' that has reinforced negative assumptions about older people.

5.1. Education and training

Educational objectives can include attempts to change thinking, feeling or behaviour with the objective of improving social care for older people (Tadd and Dieppe 2005, study). Many social care professionals who work with older people may not have the specialised knowledge and skills required to meet their needs effectively through a lack of specific education and training. A gerontological curriculum module in social work practice proved successful in increasing knowledge about assessment and intervention with older people and enhancing positive attitudes towards them especially by undergraduate students (Olson 2002, study). Askham (2005, study) considers how education can promote the dignity of older people and argues that there are a number of challenges in the promotion of dignity within professional education, for example, inconsistencies in development of professional values, curriculum contradictions such as those between education and management and for direct care of older people, the balance between theory and practice, and education for practice changing real-world conditions. 'Much of the curricular of social or health care students is not about how to work with people but how to manage work or how to categorise clinical or care situations. Such topics will not help students to see their patients or clients as individuals.'

Summary

Ageist attitudes have contributed to a culture that perceives older people as a 'burden' who are dependent and a nuisance. People working with older people may make inappropriate assumptions about them because of their age leading to covert discriminatory practices. Education and training can help to change negative attitudes towards older people and promote a better understanding of their needs.

6. Adult social care services

Adult social care covers a wide range of services for people who need support with daily living. This includes people with physical, sensory and learning disabilities, mental health needs, HIV/Aids, older people, and people who misuse drugs or alcohol.

Local authorities have the lead role in providing social care which is allocated on the basis of need through the process of assessment and care management. Services are either provided directly by the local council or purchased on their behalf from private and voluntary organisations and include residential and nursing home care; home care; community day centres; aids, equipment and adaptations; sheltered/extra care housing; direct payment schemes; community alarms; respite care; rehabilitation; advice, support and assistance to locate appropriate services; mobile meals; travel schemes; and protection of vulnerable adults. The social care sector includes staff in both

professional and non-professional roles that support vulnerable people living in the community and in residential care.

Publicly funded social care is means tested and subject to eligibility criteria based on Fair Access to Care Services (FACS) guidance. As the table below indicates, older people are the main users of social care services.

Estimated number of clients receiving services during the year by service type and age

England									
Service	2005-06			2006-07			2007-08		
	All Ages	18-64	65 and over	All Ages	18-64	65 and over	All Ages	18-64	65 and over
Total number of clients receiving services	1,748	518	1,231	1,774	543	1,231	1,774	553	1,221
Community-based services	1,494	472	1,022	1,522	497	1,025	1,535	510	1,025
Day Care	244	108	136	237	107	131	227	103	124
Meals	165	10	155	150	10	140	135	9	126
Home Care	596	105	491	586	106	480	577	106	471
Overnight respite - not clients home	68	19	49	57	16	41
Short term residential - not respite	64	12	51	62	13	49	77	16	61
Direct payments	37	25	13	49	31	18	67	40	27
Professional Support	444	216	228	503	248	254	506	255	251
Equipment and adaptations	499	112	387	491	109	382	520	119	400
Other	120	46	74	126	51	75	129	54	75
Residential Care									
Independent sector residential care	207	50	157	203	49	154	199	47	152
LA staffed residential care	32	4	27	28	3	24	25	3	22
Nursing care	108	11	97	105	10	94	102	10	92

Source: From Table 3, *Community Care Statistics 2007/08: Referrals, Assessments and Packages of Care for Adults, England*, NHS Information Centre

Although social care is a widely used term it is not precisely defined and can be interpreted in varying ways. How it is defined or understood in practice may influence the type and levels of service provided for different groups of clients. Percival (2003, review) broadly describes social care as 'delivery or facilitation of appropriate support to people in their own homes and in the wider community by statutory agencies, in particular the social services department as well as specialist voluntary organisations'. *Putting People First* (HM Government 2007, policy document) officially introduced the concept of a personalised adult social care system where people will have maximum choice and control over the services they receive. Social care services should respond to the individual instead of the person having to fit the service. 'Personalisation reinforces the idea that the individual is best placed to know what they need and how these needs can be best met' (SCIE 2008, guide). This means people who are eligible for social care get support that is tailored to their needs, and through this produce better outcomes for themselves and thus have more control over their lives (Henwood and Hudson 2007, study).

6.1 Services for older people

People over 65 years of age requiring social care are referred to generic services for older people. People aged between 18 and 64 requiring social care generally are referred to services to support their particular needs, such as mental health, learning disability, physical disability or sensory impairment. Transition between services can be triggered by age rather than need (see section 16 and CPA's companion review of ageism and age discrimination in mental health services).

The CSCI's *State of Social Care Report* (2009, study) found local authorities identified the question of equity between different groups of people using services and whether some people are supported to achieve greater independence and to exercise more choice than others. These questions arose most frequently in relation to support for older people. Concepts of independence and social care are often interpreted differently and more restrictively for older people than for other adult client groups (Help the Aged 2002, study; Levenson 2003, study; Henwood and Harding 2002; Oldman 2002, review). Older people 'continue to be perceived as passive recipients of care first and foremost' (Bowers et al 2009, study) and have to submit to a medical model of later life if they receive health or social care services (Oldman 2002, review).

The disability movement has strongly influenced the ethos of support for younger people with disabilities rejecting the concept of 'care' with its notions of people as passive and dependent recipients, 'Care as a concept has symbolised a century-long confinement of disabled people into institutions and of lives controlled and colonised by others' (Kroger 2009, review). Disability is conceptualised taking a 'social model' approach which treats the disability as residing in the disabling social treatment of the person with the impairment compared with the 'medical model' approach that treats the individual's impairment as the locus of the problem (Swain et al. 2004, review). The concept of 'independence' means having choice and control over one's life, rather than doing things for oneself or living on your own.

'Independent living' as the basis of access to individual, family and social life has only relatively recently been extended to older disabled people in the *Independent Living Strategy* produced by the Office for Disability Issues (ODI) in 2008. The *Strategy* defines independent living as: 'having choice and control over the assistance and/or equipment needed to go about your daily life'; and as 'having equal access to housing, transport and mobility, health, employment and education and training opportunities'.

The independent living model centres on the notion of citizenship and self-determination, which is about being able to make personal choices and having support to carry them through (Henwood and Hudson 2007, study). The strategy recognises that anyone, whatever their level of impairment, can

express preferences and therefore express choices about how their needs should be met. 'Disability studies have pointed out many serious problems that are built into the structures and ideologies of current care service systems and policies... Many of the physical and social barriers experienced by disabled people are shared by older people' (Kroger 2009, review). Services for older people have been slow in adopting the philosophy of independent living and user-led practices (Bowers et al 2009, study).

The disability movement has promoted the use of direct payments and Individual Budgets (IB) to give people choice and control over their lives. The process of trialling Individual Budgets raised 'questions about the role and legitimate boundaries of publicly-funded adult social care provision ... Both conventional assessment and the (often mediated) self assessment processes developed during the IB pilots focused on risk and need, a focus that has arguably been sharpened by the recent history of tight funding constraints. Thus, both social care staff and users may have become accustomed to social care provision that prioritises meeting personal care needs and avoiding crisis. In contrast, the IB pilots encouraged resources to be used in new and creative ways that focus on goals, outcomes and inclusion' (Glendinning et al 2008, study).

In the process of establishing IBs a number of sites found older people under assessed their own needs and this was put down to a consequence of older people having low expectations. In contrast people with learning disabilities and physical disabilities were likely to over assess their needs. This was attributed to a longer history of campaigning for their rights and greater sense of entitlement (Glendinning et al 2008).

Age Concern England (2007, campaign) in their report *Age of equality?* state that '... age discrimination remains part of the fabric of a social care system in which services for older people and younger adults have been managed separately, with very different standards and expectations. Older people have to make do with poorer services and a system that neglects their social needs and wellbeing. Community services such as shopping, cleaning and social activities may be all that is needed, but funding for this support has been systematically eroded.'

Summary

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. The disability movement has strongly influenced the ethos of support for younger people with the concept of independent living that has only recently been extended to older disabled people.

7. Expectations and aspirations

An overarching theme is the low level of expectation by older people of what they will receive from services and providers of services limited views of what is acceptable to older people in terms of quality and choice compared to the population as a whole (JRF 2004, study; Bowers et al 2009, study).

7.1. Service providers

There is a tension between older age viewed as a period of decline and a more positive view taking an active approach to meeting the needs of older people - 'some service providers continue to see older people in nihilistic or stereotyped ways' (Askham 2008, review). Older people's services are based on chronological age, 65+ years, associated with retirement, withdrawing from the workforce (as retirement age currently set) and possibly by implication from society. 'The institutionalisation of retirement has encouraged the view that, past a certain age, an individual's economic and social worth is diminished' (Breda and Schoenmaekers 2006, review).

'A 65 or so cut-off is arbitrary ... The biggest client group is 80 plus – very few people under this age are getting older people's services... The over-75 or over-80 age group [needs] a special focus rather than a simple age cut-off.' [Director, Social Services] (Roberts et al 2002).

Ageist attitudes might lead care managers to assume that a more restricted kind of life was suitable for anyone over 65 (JRF 2004, study; Walker and Walker 1998, study). The final State of Social Care report (CSCI 2008, study) suggested institutional ageism identified within research 'raises questions about wider cultural norms and mores' leading to an expectation that older people were expected to accept a different and inferior quality of life. An example given is that it is accepted that older people can move into a home with thirty or forty other people, but 'Forty people with a learning disability living in a hostel has long been regarded as outrageous.'

From a survey (Roberts et al 2002, survey) of 100 managers in health and social care, respondents in social services were the most consistent in identifying 'institutional' discrimination, i.e. discrimination inherent in the service design promoting dependency and limited choice, partly due to lack of resources and a legacy of historical ageism whereby previous patterns of service become the 'norm'.

We expect to pay significantly higher amounts for residential care for younger adults. It's historical, based on lower expectations ... Some of that will be realistic and some is 'that's the way we've always done it.' [Director, Social Services] (Roberts et al 2002).

A review of progress against the National Service Framework for Older People (Healthcare Commission et al 2006, review) concludes that discrimination arising from ageist attitudes continues to have a negative impact on older people's experiences of public services. Older people reported a change in attitude and availability of services when they reached 65. An example given is older people in a day centre received less funding for activities and a less varied programme than people with physical disabilities.

In their review of the literature on social exclusion among older people, Phillipson and Scharf (2004, review) identify age based discrimination as a factor limiting people's 'life chances'.

'Age based discrimination refers to the impact of ageism within economic and social policies that contributes to various forms of social exclusion in old age. The debate around ageism has challenged the link with age as a form of dependency. It emphasises instead various different forms of positive engagement that can be maintained throughout the latter half of the life course.'

Phillipson and Scharf draw attention to the literature that argues 'the case for shifting the focus of community care to that of "enhancing quality of life rather than the narrower one of reducing individually-defined risk"' (quoting Tanner 2003).

7.2. Aspirations of older people

There is evidence that older people do have aspirations for a good life based on their own ideas of what constitutes a life worth living. This involves ongoing negotiation between losses and gains (JRF 2004, study) 'fears for a future of limited resources, decline and dependency can exist alongside not only the desire to live longer but also the positive anticipation of forthcoming events and strong inter-generational relations' (Clarke and Warren 2007, study).

In a study of what older people say they want from services they 'stressed that they are individuals, with different histories, different hopes and dreams, and different priorities in the management of their lives' (Clough et al 2007, study). Clarke and Warren (2007, study) undertook a series of biographical interviews with 23 people aged 60-96 years to illuminate the concept of active ageing. Older people revealed future hopes and concerns, focusing on ordinary everyday activities around needs, deeds and relationships showing the need to offer choices for life to be lived at all stages.

Aspirations relating to a broader concept of quality of life for older people include retaining independence and autonomy, being in control, having choices about how you live, and having your priorities respected (Harding 1997, study; Henwood and Waddington 1998, study).

these aspirations are common to all older people, not just those who are relatively active and healthy ... the evidence from older people themselves is that inclusion and quality of life are just as important to those whose health or mobility are impaired as it is to more active older people. (Harding 1999, study).

Service responses need to be defined and driven more by older people to remove barriers created by other's expectations of how their lives should be lived. Older people report 'frustration both about the services provided for them and about the fact that society constantly frames their lives in terms of loss and 'risk management' (JRF 2004, study).

7.3. Hearing the voices of older people

The Labour government introduced a 'modernising agenda', with initiatives to transform services and engage in a collective debate on planning for an ageing society. An important element of the agenda for change is 'listening' to people and involving service users and their representatives in service design. 'As well as being listened to in decisions that affect individuals, older people's voices need to be heard in the wider debate about the ageing society' (Housing 21 and Counsel & Care 2009, study).

As Peter Beresford (Beresford and Davis 2008) acknowledges, service users, and groups who work to make their voices heard, still too often complain of tokenism. Although older people make up the largest section of social care service users, participatory arrangements frequently pass many by, offering them little real voice. He goes on to say 'Imaginative approaches need to be developed to encourage everyone to engage. This concerns those service user groups facing particular barriers. Involvement has to mean more than meetings, committees, surveys and conventional public speaking skills.'

Parry et al (2004, review) found older people's forums provided an important mechanism for mobilising the voices of older people and drawing attention to service needs and gaps. Harpenden Seniors Forum (HSF), for example, runs a Household Assessment Team which offers to contact agencies, charities and helpers in the town to ensure older people can get the services they require. However, as Parry et al note, there is a broader issue of how to enable more older people to engage with and make use of the forums that have good connections with statutory and voluntary service providers. 'Too often, older people find themselves isolated rather than linked into local community networks' (Housing 21 and Counsel & Care 2009, study). Support to access the internet can be one way of enabling older people to communicate within local networks and share information.

Scourfield (2007, study) in discussing citizenship and older people in residential care finds that 'a close examination of the membership of the various fora, panels, survey groups, focus groups,

reference groups and steering groups reveals that the voices of older people in residential care have not been captured adequately'. They have tended to focus on those older people in their 'third age' who are living in the community. He questions, therefore, whether these 'listening' initiatives have proved to be inclusive and representative of all older people.

In terms of policy on long term care and service delivery, Bowers et al (2009, study) found that the voices of older people with high support needs are 'so quiet as to be practically silent, or indistinguishable from the other people who speak on their behalf (professionals, relatives, commissioners, policy makers and politicians)'.

Advocacy and information are critical structures in enabling older people to access services. In a broader context, advocacy can empower and 'enable older people to find and use their own voice wherever possible', as well as being about having someone speaking up on their behalf if needed (Dunning 2005, study). Advocacy also supports citizenship as 'older people may need to be informed, advised or represented in order to secure and exercise their rights and entitlements as citizens. This relates both to basic human rights and to consumer rights and entitlements to particular goods and services' (Dunning 2005, study).

Parry et al (2004, review) examine the range of support needs that older people have and look at how these are or are not met relating to health services, transport, home-based care services and other forms of support. The authors found that in many cases older people would have benefited from an advocate who could act as a channel to communicate on their behalf as they had problems gaining access to desired services, were put off by previous bad experiences or were reluctant to bother people. They therefore missed out on receiving support that would improve their lives and could help to prevent further deterioration of their circumstances. The authors conclude that a general lack and inaccessibility of advocates increased the pressure on a vulnerable group of people and 'while they would like to receive a particular service, they felt uncomfortable, unconfident, or simply not entitled to receive them'.

Summary

Institutional ageism leads to an expectation by 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, although the voices of older people are still not being heard at all levels. Advocacy and advocacy schemes can practically support older people to shape their own lives and futures.

8. Assessment and care management

Under Section 47 of the Community Care Act 1990, a local authority is required to assess the needs of any person who appears to them to be in need of community care services. Assessment is the gateway for people accessing adult social care services. Assessment and care management covers the process of receiving referrals, assessing need, defining eligibility, arranging for packages of care to be provided and reviewing the quality of and continued relevance of that care, including field social work costs.' (NHS Information Centre 2009). The principles of holistic assessment and the social model of disability are embedded in the government policy of personalisation with a focus on outcomes.

There is some evidence older people may not experience holistic/personalised assessments in practice leading to less favourable outcomes than other adult client groups because of ageist and discriminatory practices. The focus and quality of assessments are different for older people compared with adults under 65 years. Social care services for older people are typically more concerned with physical needs and issues of safety than with enabling participation or inclusion and is therefore more restricted than for younger disabled people in similar circumstances (Help the Aged 2002, study; SPAIN, 2005 as quoted in Age Reference Group on Equality and Human Rights, 2005).

In a speech at the 'Practicalities and Possibilities Conference' (9 July 2007), Dame Denise Platt, at that time chair of CSCI drew attention to the culture change required to embrace personalised care 'Rather than focusing on what people lack, social care assessments should concentrate instead on what people can be helped to do – what things are important to them. ... It's all about a change in mind-set and culture.' People who use care services should be at the centre of all decisions about the care and support services they use.

Glendinning et al (2006, review) in their study of outcomes-focused service for older people found that while 'research into experiences of personalising services is as yet very limited', the importance of having a say in how services are delivered is an important 'process outcome' for older people. They define outcomes-focused services as 'those that aim to achieve the goals, aspirations or priorities of individual service users'.

The pressure on resources and professional assessment of risk can inhibit the development of person centred assessments for older people:

Assessment, which was seen as the cornerstone of good quality community care and responsive service commissioning, has become a rationing device. Some people do not even

manage to gain access to an assessment, never mind the services that might follow from it' (Parker 2000, review).

Ware et al's (2003, study) study of local authority practices found 'a prime focus on financial controls and the routinisation of tasks' in assessment and care management for older people.

8.1. Focus of assessment

The focus on social care for older people tends to be on maintenance with task based activities such as assisting with washing, dressing and eating, rather than enabling people to participate in social and community life.

'We ask about their daily living tasks. Whether they're independent on getting up. Whether they can do their meals. What benefits they receive. Is anyone helping them with shopping? How do they do all that?' (Hay 2004, quoted in Clough et al 2004, study)

'If you are asking, do we go out and do some totally objective assessment completely free of any kind of decisions and then kind of match services to the assessment after, the no we don't ... we concentrate our energies on the risks and if we deal with anything other than the highest risks then it's in a very inconsistent and ad hoc way'. (Hay 2004, quoted in Clough et al 2004, study)

Younger adults with disabilities receive an additional aspect of help to enhance their quality of life and remain active within society (Help the Aged 2002, case study seven local authorities).

'Its [age discrimination] very noticeable when assessing the needs of younger persons ... 'Do they have a social life?' and so on. For older people we take a much more basic view.'
[Director, Social Services] (Roberts et al 2002, survey)

Older people also benefit from social participation. A study of differentials in mortality among older people in East London and Essex revealed social participation was 'associated with lower risks of death, particularly among those aged 65 to <85, and that life satisfaction is also protective, particularly among females and people aged 85+, even when health status and socio-demographic circumstances are controlled' (Bowling & Grundy 2009, study). This is supported by findings from nine focus groups with older people to discuss what they want from community health and social care services. Two priorities identified are 'focusing on the wishes and aspirations of the individual rather than a series of tasks' and 'recognising the impact of isolation and the role that social care can play in combating this, and in improving wellbeing'. One respondent summed it up 'Social care needs to include the "social" aspects as well as the "care" aspect' (Age Concern 2006, group study).

An analysis of two qualitative data sets of 100 in-depth interviews of older people in receipt of formal care service at home and in residential care found both groups had emotional, social and practical needs which were not being met. 'Of importance to all the older people in the study was the quality of everyday life. Having enough to do and social relationships were more salient than the technical language of quality assurance, care plans, care reviews' (Oldman and Quilgars 1999, study).

The scoping review of person centred planning in social care by Dowling et al (2006, review) covers all service user groups, with greater attention on services for people with learning difficulties. It becomes clear through study of the literature that there is a strong bias towards the voices of practitioners and academics i.e. the perspective of service users is not being represented. While the voices of people with learning difficulties are becoming more audible the voices of older people are not being heard. Person centred planning/care takes on different meanings within the lives of different service users. Most of the evidence to date focuses on people using services for people with learning difficulties.

8.2. Quality of assessment

The CSCI (2008) report on the state of social care in England 2006-07 found differentiated approaches to various groups of people evident throughout the process of assessment, with 'less comprehensive information collected about older people'. Inadequate assessment may fail to address individual needs and it concluded 'older people were likely to be disadvantaged compared to other people' seeking social care. One reason for the difference in approaches may be the greater volume of older people requiring assessments. In 2007-08, of 661,000 new clients with completed first assessments, 79% were classified as having a physical disability, frailty and sensory impairment, 16% mental health client, 3% vulnerable people, 1% learning disability, and 1% substance misuse. The 75 and over group age group constituted 90% of the physical disability, frailty and sensory impairment group and 3% of the vulnerable group (NHS Information Centre 2009). The response times for assessments, designed to ensure people receive timely assessment and subsequent services, may have the unintended effect of reducing the amount of time spent doing the assessment with older people. From December 2004 the DH targets for waiting times and take up of care packages for all assessments of older people are that assessments will begin within 48 hours of first contact and will be completed within 4 weeks (with 70% within 2 weeks).

Little's report, *Improving Older People's Services* (2002), noted that:

Overall assessments were of good standard, but with some important shortfalls such as the lack of personal information. Care plans were often too service led. This was linked to the volume of work, the need to complete it within reasonable timescales and to shortages of

local resources. There was also a lack of creative thinking about how best to devise a personalised plan for older people, drawing on their strengths as well as their needs.

Older people may not be able to access the necessary specialist care assessments or specialist advice and information because of their age. For example, older people with sensory impairment may experience indirect discrimination as failing eye sight increases with age and it affects proportionately higher numbers of older people. There is evidence that social services departments are failing to assess properly needs arising from older people's sight impairment leading to social exclusion 'poor quality social care, which inadequately addresses or ignores important needs, may exacerbate difficulties and lead to social withdrawal or a sense of alienation' (Percival 2003, review). The findings from a major survey of 588 blind and partially sighted adults in England, Scotland and Wales suggest that services for people in Britain who have lost their sight are not sufficient and do not reach most of the people in need of help. It highlights the sparse nature of support for a growing older population encountering sight problems in later years (Vale 2004, survey).

Age discrimination is a factor in both identification of visual impairment in older people and provision of services and support - the suitability of low-vision aids and assistive technology, mobility and rehabilitation training, emotional support and information in accessible formats - to meet the needs of older people with sight problems (Smith 2006, study).

There is evidence that depression in older people may be overlooked in assessments. Qualitative interviews were conducted with 20 social care practitioners working in generic services for older adults in south London to elicit the perceptions and conceptualisations of this condition among social care staff, and views on how the response of social care and other agencies might be improved. Depression was perceived to be remarkably common among clients, a phenomenon largely attributed to the adverse circumstances of old age, particularly social isolation. A key message from participants was that social causes indicate a need for social interventions and the expansion of social, recreational and psychological interventions was advocated (McCrae 2005, study).

The quality of assessments is a particular issue for older people being discharged from hospital – 'Rapid discharge was only achieved at the expense of proper planning with the older person concerned' (Healthcare Commission et al 2006, review). 'They assessed whether you could dress or get tea. If you can do that you are fit and well' (Help the Aged 2002, study). A national report on rehabilitation and remedial services for older people (Audit Commission 2000, review) stressed the importance of comprehensive assessment for older people who may require additional support to regain their best possible functional independence and confidence compared to younger adults to

reduce the risk of readmission to hospital or being 'misplaced' in long term care. An audit of nursing home placements in England and Wales found 90% of records contained no physiotherapy or occupational therapy reports of pre-admission assessments 'if the lack of documentation reflects a lack of formal therapy assessment, this would indicate a national failure of multidisciplinary assessment prior to the referral and placement of older people in nursing homes'. (p. 48)

A study of hospital discharge from the older person's perspective concluded that participants 'felt disempowered in terms of exercising any real choice in decisions about their transfer to the community'. Older people in the study actively or passively relinquished their involvement in the processes of discharge planning because of the perceived expertise of others and feelings of disempowerment (Swinkel and Mitchell 2008, study). A qualitative synthesis of research on older people's views of hospital discharge (Fisher et al 2006, review) found that risk management and safety are priorities within assessment for staff planning discharge with plans matched to existing services, but they fail to take into account longer term life planning issues of importance to older people. Older people's lack of participation in discharge planning – often attributed to passivity on the part of older people but disguising a host of reasons – was a consistent theme.

Summary

The quality of a person's assessment is at the centre of receiving appropriate support. There is evidence that older people's assessment of needs in practice leads to less favourable outcomes than other adult client groups because of ageist and discriminatory practices. Assessments and care packages for older people are more mechanistic focusing on personal needs and risk, which are obviously important, but other spheres relating to quality of life such as emotional, psychological, social and spiritual needs are not as well supported. The assessment continues to be service led rather than needs led.

9. Eligibility criteria for accessing adult social care

The Department of Health published Fair Access to Care Services (FACS) in June 2002, which provides councils with a national framework for setting eligibility criteria for adult social care. The eligibility framework is based on risks that arise from needs associated with various forms of disability, impairment and difficulty. The guidance prioritises the risks faced by individuals into four bands - critical, substantial, moderate and low - and requires councils to adopt these bands in determining their criteria. FACS was introduced principally to standardise decision-making processes across local authorities and minimise the post code lottery of social care allocation. However, the way local authorities are using eligibility criteria to ration services and allocate limited resources has particular implications for older people.

For the 2008-2009 financial year, 73% of authorities set Fair Access to Care bands at substantial, with the remainder at moderate (27%) (LGA). In 2005-06, 58% of councils operated just at the highest two levels (DH 2008 disability equality report). As a result of elevated thresholds an increasing number of people with 'lower' level needs receive no support, there is an increasing concentration of resources at those with the highest level of need, and people excluded from the system have difficulty finding any sort of support (CSCI 2008; Hudson and Henwood 2008, study; Counsel & Care 2007, survey).

The CSCI (2008) review of eligibility criteria in practice, *Cutting the Cake Fairly*, draws attention to the differing interpretations placed on the Fair Access to Care Services guidance by local councils. It suggests that some practices are contrary to the intention of the guidance, and has concerns that additional rules introduced by councils may exclude certain groups of users. It is argued that younger people receive more substantial care packages to remain within the community, while older people who would most benefit from 'low level' and preventive support are excluded from receiving it through tightening of eligibility criteria and can be obliged to go into residential care as a result (Raynes et al 2006, study).

Low level support has become equated with less effective or worthwhile support, but for older people it can be particularly important in maintaining independence and control. 'Failure to provide this not only discriminates against older people, but increases the risks they face in the home.' (Help the Aged 2002, study; Levenson 2003, study; Henwood and Harding 2002; Clough et al 2007, study; LGA 2008, 2009, policy document; Raynes et al 2006, study)

'Resources targeted towards the most in need and not towards lesser priorities discriminates against younger old people [so that] more people are at greater risk of breakdown. There is no satisfactory formula [to quantify the effectiveness of more preventive approaches]. [Director, Social Services] (Roberts et al 2002)

In a study examining the commissioning of care services in seven local authorities (Ware et al 2003), care managers expressed concerns that users' emotional and other broad quality of life needs were not met under increasingly strict eligibility criteria which attended to direct physical needs only. The authors suggest that because older people have less control over their lives through physical disability 'it is even more important to meet their psychological, emotional, social and spiritual needs'.

In a response to the CSCI review, Age Concern suggests 'the current problems stem from lack of resources rather than any inherent failings of FACS guidance' (ACE/Lowe 2008, study). It goes on to say that FACS 'combats age discrimination by excluding age as a basis for rationing services and

bases eligibility on risks to all aspects of independence, not just risks on safety'. The problem is the local authorities diverging from national guidance allowing rationing by age to take place covertly. CSCI suggests LAs are misinterpreting the four bands, equating low level service with less necessary service, but this indirectly discriminates against older people needing 'That Bit of Help' who are disproportionately affected by this decision.

Clough et al (2007, group study) found that many authorities did try to provide low level support services to include befriending schemes, advocacy, low-level domiciliary care, respite care, luncheon clubs, benefit advice/debt counselling, black and minority ethnic outreach and support service. Practitioners did record unmet needs in assessments even if it did not necessarily lead to a service to address the need. Lack of funding was the main constraint to providing low level support services.

'Almost invariably, care packages are made up of services procured through block contracts and consist of traditional services that support personal care needs such as home care, meals, day care and residential care. "Spot purchases", that is services that are tailored to meet individual needs, are rarely, if ever, available.' (Clough et al 2007) Practitioners are encouraged to use block purchased services, and time constraints inhibit them from seeking alternative low level preventive schemes.

'We've got a declining number of people on statutory provision and a growing population of older people – and what are we providing? Two hours of home care a week [for older people] ... Even preventive services are about avoiding high-dependency cases – they aren't truly preventive at all. [Director, social services] (Roberts et al 2002)

Summary

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. Care packages are restricted to traditional services and not always tailored to older people's individual needs, including their psychological, emotional, social and spiritual needs.

10. Age related benefits and grants

Attendance Allowance (AA) and Disability Living Allowance (DLA) are universal benefits that provide disabled people with additional income because of the increased cost of living with a disability. Strictly they do not come within the remit of this review as they are not administered locally within social care, however, discussion is included as access to different levels of disability funding streams and grants is determined by age rather than need and is discriminatory towards older disabled

people. This has an impact on the quality of life of older people. Attendance Allowance (AA) is payable to people over 65 with highest rate set at £70.35 and the lowest rate set at £47.10. Disability Living Allowance (DLA) for people under 65 is in two parts - the care component and the mobility component. The care rates are set at £70.35, £47.10 and £18.65. The mobility rates are set at £49.10 highest and £18.65 lowest. The maximum total weekly rates for AA are £70.35 compared with DLA at £119.45. Some disabled people may keep their funding package when they reach 65, but Disability Living Allowance is not available to people who become impaired after 65.

The Independent Living Funds were set up as a national resource dedicated to the financial support of disabled people to enable them to choose to live in the community rather than in residential care. People over 65 are not eligible to apply for support from Independent Living Funds but once they are in receipt of funds they may continue to receive them after 65.

An older person using the Independent Living Fund highlighted the inequity of people aged over 65 being unable to qualify for ILF support, and the implications of this for the opportunities in their daily lives:

'One of the things I have about ILF – and it doesn't affect me because I qualified for it before I was 65 (...) is that I could be next door to someone with the same level of impairment. I was diagnosed and got ILF before 65, [but if] they didn't apply – they have an existence; they get up in the morning and get fed, they get showered and they get put to bed again. But I can go to the cinema, I can go shopping. Yet it is just because of an age – that one person can't have a life.'(CSCI 2009)

Summary

Disability allowances are age related and directly discriminate against older people who receive lower allowances if taking them up after 65 years of age. Some disabled people may keep their more generous funding package when they reach 65 giving rise to a two tier system. People over 65 are not eligible to apply for support from Independent Living Funds but once they are in receipt of funds they may continue to receive them after 65. The differential access to funds allows for greater flexibility and potential for innovative approaches to meeting support needs for younger disabled people compared to older people with disabilities.

11. Allocation of resources and funding

11.1. Social care budget

Justin Keen and David Bell note in their paper 'Identifying a fairer system for funding adult social care' (JRF 2009, review) there have been several detailed analyses on the funding of adult social care

and a shared conclusion from the analyses is that 'the current system is underfunded' (Help the Aged 2002, study; Hirsch 2006, study; Wanless 2006; LGA 2008, 2009, policy documents; Lloyd 2008, study).

'There are several areas where current evidence points to unmet need. One concerns quality - for example, where cost containment has resulted in poorly trained staff, low pay and high turnover. A second emerging shortfall concerns supply - with, for example, a recent fall in the number of 'low-level' domiciliary care packages. Third, affordability of domiciliary packages is an issue, with evidence that some people on modest incomes are having in some cases to pay large amounts to get adequate care in their homes.' (Hirsch 2006, study)

It is generally acknowledged that social care is awarded a low status, with a limited political priority and little public awareness or understanding. A YouGov survey of 1,993 adults across Britain undertaken in April 2009 found confusion about the nature of social care services and misconceptions about who pays for care; only 46 per cent of people were aware that care provision is means tested (IPPR/PriceWaterhouse Coopers 2009, survey). Service users have highlighted on occasion the inadequacy, unreliability and poor quality of much social care provision. Problems of abuse and neglect regularly emerge in social care settings, particularly in residential institutions (Beresford 2008, review). A low value is placed on care workers, judging by their poor levels of pay, conditions of work and levels of training. The Secretary of State for Health Andy Burnham, in an interview with *The Guardian* (Brindle 2009) acknowledged that 'Social care workers who look after older and disabled people have had a raw deal under successive governments and should be paid more and given greater status.' In the same interview he said 'Pressure on social care budgets has kept down pay rates and undermined the quality of care given to some of the most vulnerable citizens.'

It has been estimated that at least an extra £200 million per annum will be required over the years 2011-2014 to support people with learning disabilities who require social care; the number of people with learning disabilities requiring social care will increase by at least 3-5% annually on average over the next 5 years (Learning Disability Coalition 2009, campaign). Figures from the Wanless review, which looked at services for older people over 65 suggest that the amount spent on older people's care may need to rise by 50% to achieve necessary services, more care overall and better pay for care workers (Wanless 2006).

11.2. Allocation of resources within adult social care

Local authorities allocate funds for social care but the process is not transparent. Funding by central government for social care is not protected and there is concern that pressure on resources means

older people lose out disproportionately to other priorities (SPAIN 2001, 2005, campaign). There is evidence of a lack of funding of services that older people value (JRF 2007, study). These services range from domestic cleaning, laundry, household and garden maintenance to safety and security, mobility aids not subject to occupational therapist assessment, help to go out and companionship to reduce social isolation.

In 2007-2008, of the £15.3 billion gross current expenditure spent on adult services the majority of monies was spent on services for older people, £8.8 billion (57%) who constitute the largest group requiring support. The greatest rise in gross current expenditure between 2006-07 and 2007-08 in real monetary terms was for adults with learning disabilities which saw an increase of £62.5 million (2%). Conversely expenditure has fallen for older people by £148 million (2%) (NHS Information Centre 2009, personal social services). The 'Adults' social services expenditure survey 2008-2009' carried out by the Local Government Association has identified care home placements for people with learning disabilities as the most significant area in terms of both demand/volume and unit cost/complexity cost pressures (LGA and ADASS 2009, survey).

The CSCI's report of the state of social care in England 2006-07 (2008) concluded that in all six councils reviewed eligibility criteria was used to set priorities and control social care expenditure amongst groups - 'meeting the high costs of younger adults with complex needs had knock on effects for all groups' and the 'high cost support for small numbers of people with learning disabilities was often cited as reason for budgetary deficits.'

The same report found that levels of non-residential services provided by councils, particularly home care were tightly rationed by the setting of thresholds for eligibility for services. Since 1997 the numbers of households receiving supported home care has fallen from 479,000 to 358,000 in 2006 'It is estimated that around 6,000 older people with high support needs and 250,000 with less intensive needs receive no services and have no informal care' (CSCI 2008).

Forder states in his paper 'The costs of addressing age discrimination in social care' (2008, study) that 'Historically PSS [personal social services] expenditure per head on older people using social care services has been lower than for other adult client groups' and 'this difference is taken as a possible indicator of age discrimination in the distribution of services', although there may be 'legitimate' reasons for a pattern of spending. He set out to determine whether people in different age groups are treated differently after the 'legitimate' differences are removed. He analysed two datasets, The British Household Panel Survey (BHPS) and the national evaluation of individual budgets (IBSEN), controlling for appropriate needs factors, to determine differences in levels of support between age groups. The IBSEN data shows that 'at an individual person level, after

controlling for needs and outcomes, the support (ie cost weighted service utilisation) received by older people is significantly less than the support received by younger people'. 'Older service users (65 and over) would require a 25% increase in support for these age differences compared to younger people (aged 18 to 64) to be removed'. The data from the BHPS panel also suggests, although less strongly, that older people's access to services is more limited than younger people. Forder concludes that 'the balance or resourcing should therefore change, whether it comes from a redistribution or extra spending on older client groups'.

The pilots on Individual Budgets (IB) served to highlight discrepancies in packages of care available to older people and younger adults through transparency of the Resource Allocation System (RAS) 'it is clear that there are institutionalised inequalities in the resources allocated between different groups of people who use social care services' (Henwood and Hudson 2008, review). People with learning disabilities had more social care resources allocated to leisure or social participation activities than other user groups. Older people do not have access to some funding streams – a restriction based on age. 'The levels of resources allocated through IBs to working age people with physical or sensory impairments were relatively high, particularly compared to older people. People with physical or sensory impairments were also more likely to be able to access additional funding streams such as the ILF. It is therefore likely that these more extensive allocations of resources offered greater flexibility and more opportunity for innovative approaches to addressing support needs' (Glendinning et al 2008, study).

11.3. Funding for home care and residential care

The differential funding of care packages for older people and younger adults with disabilities is explicit. Lower rates are paid for home care and residential care packages for older people than for other adult service user groups. While there may be legitimate reasons relating to higher support needs and market forces reducing unit costs, such differences can have a significant impact on the type of support provided for older people. Older people are seen as a single group with similar needs rather than individuals with differing needs. The widespread use of cost-ceilings for domiciliary care packages, setting a maximum per week, based on a proportion of the costs of residential placement means that older people can receive less care hours than younger adult groups. Older people 'have been offered far fewer options than other service users. Assembling a care package was often a pragmatic exercise with limited scope for flexibility, innovation and choice' (Henwood and Harding 2002)

'We've got a declining number of people on statutory provision and a growing population of older people – and what are we providing? Two hours of home care a week [for older

people] ... Even preventive services are about avoiding high-dependency cases – they aren't truly preventive at all. [Director, social services] (Roberts et al 2002, survey)

In social care, the routine use of cost-ceilings for care packages for older people can be said to reflect the assumptions that:

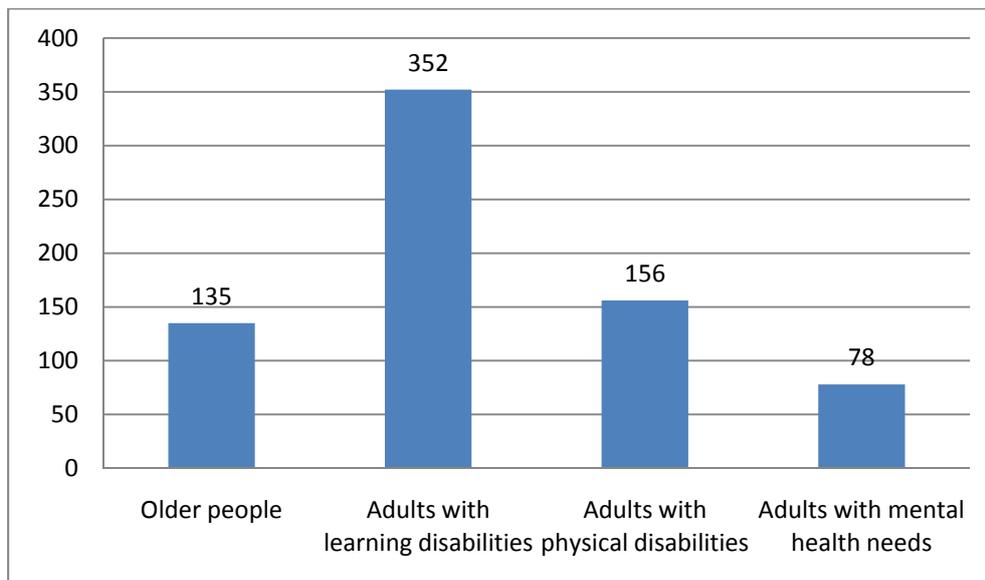
- 'Older people do not need, or perhaps deserve, the same levels of investment as younger people.
- Social inclusion is not a meaningful or relevant aim for older people's services.
- Choice and independence have a different and more limited meaning for older people, and there is less need to provide flexible, responsive or innovative services' (Henwood and Harding 2002).

In practice, cost ceilings for packages of care can trigger reviews which might lead older people being pressured to accept residential care that is considered more cost effective for local authorities at an earlier point than younger adults (Help the Aged 2002, study; Levenson 2003, study; Henwood and Harding 2002, Ware et al 2003, study).

'There have been people who have been forced into care because we've refused to fund them any further [with domiciliary care packages]. They are told "So you take your risk and stay at home or you go into care".' (Help the Aged 2002, study)

'The limit for younger disabled is much higher ... The market for older people is more 'pile em high, sell 'em cheap. But also ... there's a notion of "it's more important to keep a young person at home"' (Head of older people's strategy, Roberts et al 2002)

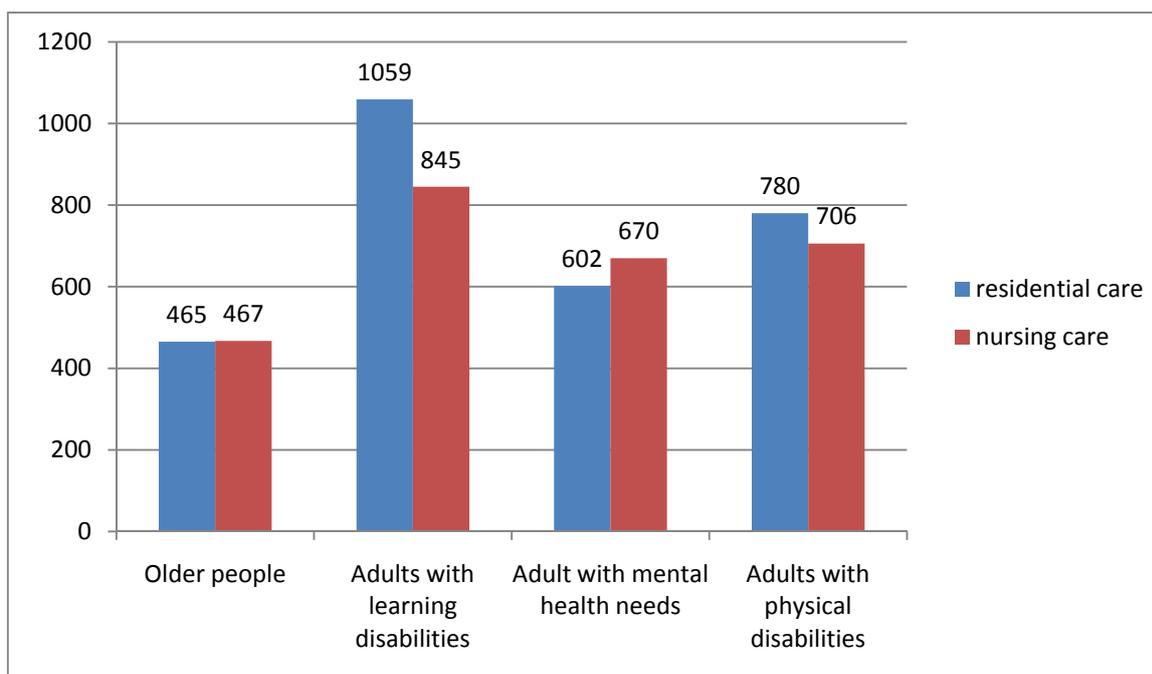
Costs per person per week £: home care, 2007-08



Source: *Personal social services expenditure and unit costs England, 2007-08*, NHS Information Centre

'Generally ... there's less per head for older people. ...[Older people are] placed in residential care homes so we don't overspend. It's discrimination because it's not how we would treat ... children, then it's 'hang the cost.' (Help the Aged 2002, study)

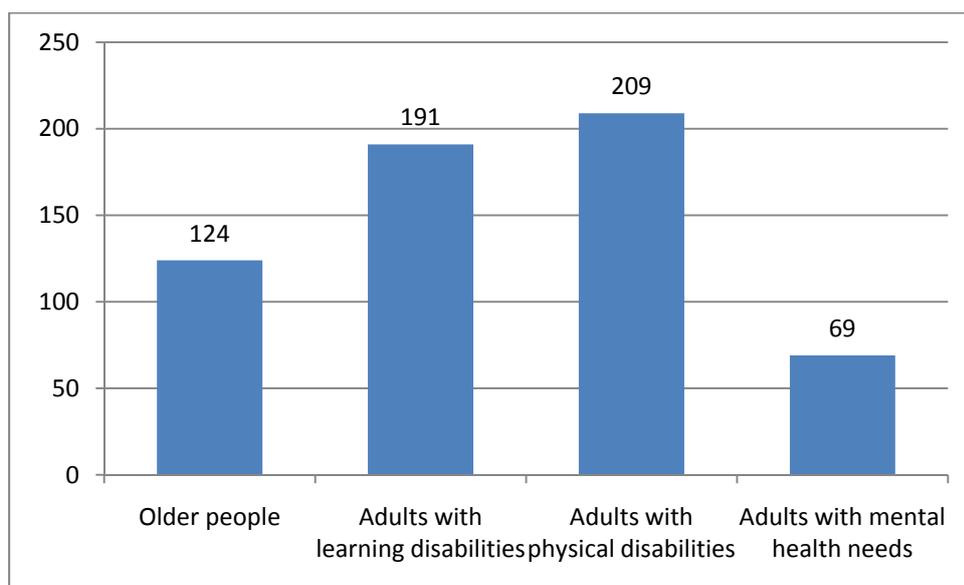
Costs per person per week £: residential and nursing care, 2007-08



Source: *Personal social services expenditure and unit costs Enaland. 2007-08.* NHS Information Centre

'So you could have an older person in the early stages of dementia or whatever it might be, who really wants to stay in their own home, but their package is going to be absolutely massive and you have got a spend ceiling for older people, so they can't have it. They have to go into residential care unless somebody tops them up, you know, their family. You could have a person with learning disability with dementia in their later stages of life being supported, and massively, to stay at home. Now that's the tension.' (Manager Learning Disability Services) (CSCI 2009)

Costs per person per week £: direct payments, 2007-08



Source: *Personal social services expenditure and unit costs England, 2007-08*, NHS Information Centre 2009

Direct payments and individual budgets are a route to individualised services but fewer older people are accessing these resources compared to younger adults. In 2007-08 it is estimated that 27,000 older people in England received direct payments compared to 40,000 younger adults (NHS 2008, Community Care Statistics). However, this is double the number of older people receiving direct payments in 2005-06. Bainbridge and Ricketts (2003, study) found that

‘many direct payment schemes had been designed for people of working age and did not take the particular needs of older people into account. This limited the accessibility and usefulness of direct payments. Failure to offer direct payments systematically and poor public information were further barriers. Some councils had no arrangements for advocacy or support by voluntary organisations. In others that did fund support by voluntary sector organisations, limited funding restricted access’.

Clark et al’s (2004) study of older people’s experiences of direct payments concluded that they had increased control and more choice in their daily lives with the reservation that there was evidence of age discrimination in the way there was limited access to social and leisure services compared to younger adults. The evaluation of individual budget pilots raised questions about the benefits of IBs for older people as reported outcomes showed lower levels of wellbeing (Glendinning et al 2008, study).

Summary

Pressure on resources locally is leading to tighter restrictions on services that benefit older people needing ‘that bit of help’. Historically PSS [personal social services] expenditure per head on older

people using social care services has been lower than for other adult client groups and there is evidence that at an individual person level, after controlling for needs and outcomes, the support (ie cost weighted service utilisation) received by older people is significantly less than the support received by younger people. Different cost ceilings applied to care packages for older people and younger adults with disabilities impacts on the support options available to each group. Markedly older people have a restricted range of opportunities particularly relating to social aspects of daily living. Older people may be pressured to accept residential care that is considered more cost effective for local authorities at an earlier point than younger adults.

12. Charging policies

12.1. Non-residential services

Local authorities are given discretionary powers to charge for non-residential social services. The local authorities decide on how to set charges for non-residential social services, but the government stipulates that these charges should be fair and no one should be asked to pay more than they can reasonably afford. People in different areas and even in the same area, depending on savings, benefits and grants accessed, can be asked to pay very different sums (Help the Aged 2002, study). Thompson and Mathew's study *Fair Enough?* (2004, study) on the implementation of DH guidance on fairer charging policies for home care and other non-residential social services noted there are still wide variations among local authorities in setting the level of any maximum charge, what they charge per hour and what they allow in disability related expenses.

The Coalition on Charging (2008, campaign), a group of disabled people, older people and carers' organisations, carried out a survey of members to elicit views on the impact of charging policies for adult social care services. While charging policies affected all groups, older people living on fixed incomes felt strongly that they were being discriminated against as the whole of their occupational pension is taken into account while earnings of younger people are disregarded in local authority charging criteria. Pensioners on lower incomes may be prevented from taking up required support services because of financial pressures. The Counsel and Care National Survey of Local Authority Care Charging and Eligibility Criteria 2007 (2007, survey) produced weekly charging rates for home care services ranging from £60 to £326 per week, and hourly rates from £7.55 to £17.30 per hour.

12.2. Residential services

Charges for Residential Accommodation Guide (CRAG) is the national guidance on charging for residential care. People with less than £23,000 are entitled to apply for financial help from social services. The cost of any nursing care is paid for by the NHS. Care home residents who are supported by local authorities contribute most of their income to fees. It is argued that older people are

unfairly penalised by the separate funding rules for residential and non-residential care. The boundaries between health and social care, and the division of means tested and non means tested services can lead to disjointed care and allegations of unfairness for older people. This is of particular concern for older people with dementia who need specialist care tailored to their needs. Defining a primary health care need is in many cases complex and the application is seen as unfair because a decline in older people's health has been the reason why the majority of care home residents need long term care (Poultner, Professional Social Work 2009, opinion). See the CPA reviews of primary and community health care and mental health services for further information on care homes (CPA 2009).

Older people who self fund often have to pay higher charges than those who are supported by the state. The average cost of residential and nursing care and intensive home care is £559 per week (PAF indicator AO/B12). The cost of nursing care for older people (£476) is similar to that for residential care (£465) but the cost for own provision residential care (£716) is higher than the cost of residential care provided by others (£420). The average cost of home care on a sample week basis is £14.40 per hour but the cost of own provision home care (£22.30) is higher than that for home care provided by others (£12.30) (NHS Information Centre 2009, personal social services).

Summary

Variations in local authority charging criteria may discriminate against older people living on fixed incomes as the whole of their occupational pension is taken into account while earnings of younger people are disregarded. The boundaries between health and social care, and the division of means tested and non means tested services can lead to allegations of unfairness for older people when determining eligibility for funding in care homes. Self funders often pay more for care than people supported by the state.

13. Quality of residential care

There is some indication that older people receive poorer quality of care in residential care homes than younger adults: 76 per cent of homes for younger adults were rated either 'good' (61%) or 'excellent' (15%), with 22% rated adequate and 2% rated poor compared with 67% of care homes for older people - breakdowns for these are 55% rated good; 12% rated excellent; 28% rated adequate; and 4% rated poor. The data shows considerable variability in the quality of services purchased by councils. At September 2007 one place in five (21%) for older people purchased by councils (that is some 7,700 places out of 36,500) was in care homes rated 'poor' or 'adequate'. The percentage was higher for nursing care in homes for older people (24%). The percentage of 'good' and 'excellent' places was highest for nursing care for younger adults (83%) (CSCI 2009).

A research study using benchmarking data to calculate a 'fair market fee' with 'ceiling' and 'floor' rates for care home places concludes that most public sector commissioning bodies do not at present pay fees at levels which are adequate to support and sustain a care home sector that meets all of the most recent Minimum National Standards (Laing 2008, study). The report estimates fair market fees for operating a typical, modern and efficient care home in 2008/9 and is limited to care home services for frail older people and older people with dementia in England. Outside London, weekly figures amount to £665 for nursing care, £538 for the personal care of frail older people and £556 for the care of older people with dementia with costs higher in the more affluent areas of England. Many older people receiving supported residential care are required to top up their payments to meet the actual costs.

The view of residential care as a 'last refuge' is pervasive despite research showing that for some people a move into a care home is seen as a positive step.

Key concerns are losing control over their lives, losing part of their identity, loss of personal possessions, not being valued, nursing homes being unable to meet the cultural and religious needs of ethnic minorities, lack of privacy, lack of activity, insufficient staff and inadequate training and failure to provide care at the pace required by older people (ESRC 2000, study).

As part of the My Home Life programme, an extensive review of the literature on the quality of life in care homes was undertaken by the National Care Homes Research and Development Forum (Help the Aged 2006, review). The My Home Life review details how quality of life may be compromised based on stereotypical assumptions about older people's lives in care homes.

Following the fragmentation of long-term care across the statutory, voluntary and private sectors there is evidence of ageism in policy development over the years, where old age is depicted as a problem evidenced in the management of decline in the attitude to long-term care, rather than one requiring a dynamic, positive approach to ensure that older people lead a fulfilling life (Hurtley 2004).

Quality of life is a key concept, but there is a need to think critically about assumptions made about quality of life being different for older people in care homes than it is for everyone else (Gerritsen et al 2004) 'not only is this not supported by any evidence, but it also opens the door to the use of stereotypes in thinking about older people'. Quality of life comprises several dimensions to include physical, social or psychological aspects. A considerable amount of research literature looks at quality issues from a professional perspective but few do so from the perspective of older people. 'Professional and academic literature have suggested that later life is a time of decline and

dependency, and this thinking has “inevitably under-estimated the quality of life of older people”.’ (Help the Aged 2006, review). The effective disenfranchisement of people in institutional settings contributes to their sense of loss of identity, lowering of self-esteem and a reduced sense of personhood (Scourfield 2007, review).

Increased quality of care includes promoting and enhancing the wellbeing of people. ‘Those who are able to remain socially active are likely to achieve a positive self-image, social integration and satisfaction with life’ (Barrow 1992, review). ‘Activity’ is not just an optional added extra but essential to the psychological and physical health and wellbeing of residents in homes (Counsel & Care 2007, study; Glendinning et al 2006, review).

The CPA reviews of primary and community health care and mental health services covering dementia care include discussion of how the health needs of older people are dealt with in care homes including end of life care issues (CPA 2009).

Summary

Older people may receive poorer quality of care in residential care homes than younger adults. 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.

14. Extra care housing

Tinker et al (2007, study) note ‘there is a fog of confusion surrounding the concept and little consensus on its definition’ but the essential elements are that it focuses on the enabling sort of care which encourages independence, healthy living and lifestyles. Evans and Vallely (2007) define extra care as ‘housing with full legal rights associated with being a tenant or homeowner in combination with 24-hour on-site care that can be delivered flexibly according to a person’s changing needs’. There is only a small body of empirical evidence from the UK to illustrate how well different schemes actually work.

Croucher et al (2006, review) found that ‘there are clear messages from residents across a range of settings that housing with care offers them independence, privacy and security’. While the evidence suggests that housing with care can have a positive impact on the health and wellbeing of residents, and that it is beneficial to their quality of life, the very frail and people with sensory and cognitive impairments are consistently reported to be on the margins of social groups and networks

experiencing social isolation. The capacity of housing with care to be an alternative to more institutional models of care and provide a home for life, as well as to support people with severe dementia-type illnesses, is not clear.

Alison Petch in *Community Care* (2007, review) suggested there was evidence that the wider support needs of some residents beyond immediate personal care could fall into a 'service gap'. The principles of independent living for older people, which may require support to access social networks or community activities, need to be carefully reviewed and resources accessed. Providers need to be clear as to the extent to which they seek to respond to lifelong needs or provide for a particular stage.

Housing is not specifically within the remit of this review but it should be acknowledged that inappropriate housing and community facilities have a considerable impact on the wellbeing and quality of life of older people. (See *Lifetime Homes, Lifetime Neighbourhoods: A national strategy for housing in an ageing society* DCLG, DH and DWP 2008, policy document.)

Summary

Local authorities are favouring the development of extra care homes which offer older people legal tenancy and support packages but those who are frail and with sensory and cognitive impairments may be disadvantaged in these settings.

15. End of life care

It is likely that a large number of older people do not receive appropriate end-of-life care (Department of Health 2008, policy document). Seymour et al (2005, study) found that many older people approaching the last phase of their lives, and their carers, experience systematic and structural related disadvantage and discrimination 'About half of all deaths do not take place in the setting that the dying person prefers.' The authors suggest that education and practice about end-of-life care should encourage a critical perspective on the idea that choice and control are always the most important factors in good care.

It is still the case that the 'good death' is hard to achieve ... because of a complex range of factors including their physical environment, lack of availability of basic equipment and the lack of support and appropriate training of professional staff. Until the care of the dying is afforded higher priority, many older adults will suffer the experience of either under- or over- treatment at the end of life and will fail to be provided with the good standards of comfort and symptom control that we should all be able to expect. (Seymour 2005)

Older people's ability to make informed choices can be undermined without sufficient and accurate information as they are unaware of the choices available to them and consequently unable to challenge decisions made on their behalf. In a Help the Aged study many people voiced anxieties about the process of dying, place of care and who would look after them. They generally perceived they had little control over such issues and feared dying in pain, dying in a care home or a 'geriatric' ward, or dying alone. The importance of dignity in care, including at the end of life, was considered crucial to policy planning and provision of care (2006, group study). See CPA reviews of primary and community health care, secondary health care and mental health services (CPA 2009) for further information on end of life care. There is some evidence of direct age discrimination, in that older people and younger people may be treated differently in end-of-life provisions, but the main issue is probably one of indirect discrimination through failure to provide an adequate end-of-life / palliative care service to older people.

Summary

CPA reviews of primary and secondary care suggest there is some evidence of direct age discrimination, in that older people and younger people may be treated differently in end-of-life provisions. Older people may not experience good care when dying and are not always supported to make choices when facing death. People identified as having end-of-life care needs should benefit from a multidisciplinary approach to care incorporating expertise from all health and social care professionals relevant to that person's care. Training for care workers and practitioners at all levels on end-of-life care is needed to instil the necessary knowledge, skills and attitudes (see the End of Life Care Strategy DH 2008, policy document).

16. Older people with learning disabilities

Improvements in health and social care mean that people with learning disabilities can now expect to live longer. While people with complex needs and people with Down's syndrome still have a reduced life expectancy, people with milder learning disabilities now have a life expectancy similar to other adults in the general population. A review of the literature identified large areas of need which have not been met amongst older people with learning disabilities and services are often not aware of them (Hogg et al 2000, review).

Valuing People Now (DH 2009, policy document) sets out a three year strategy to improve services for people with learning disabilities. The principles underpinning the strategy – rights, independence, choice and inclusion – are extended to older people with learning disabilities, but they are not singled out as a group requiring any specific support. Service support for older people with learning disabilities is not always based on need but can be determined by their age. Increasing numbers of

people with learning disabilities are surviving into older age. In some parts of the UK those who reach the age of 65 are transferred from learning disability services to older people's services, leading to reduced levels of support. Studies indicate that older people's services can lack the specialist knowledge to support older people with learning disabilities and they have less to spend on care packages compared to learning disability teams (*Community Care* 2007). People with learning disabilities need particular support to maintain relationships with family, friends and other intimate relationships. Older people's services are not always equipped with the appropriate skills and knowledge for meeting these special needs so that older people with learning disabilities can become very isolated (Blackman 2007). Research for the GOLD (2002) project found older people with learning difficulties had fewer supported social and leisure opportunities than younger people:

‘Limited resources, particularly relative to younger persons’ services restrict possibilities for outings and life enhancement generally.’

Age divisions in service provision can result in older people with learning disabilities being excluded from day centres for younger users through tacit policies of retirement while not being catered for in older people's day centres and they find themselves exchanging a well-supported life for a restricted existence. Day centres can be their focal point of social contact and source of friendships developed over many years from sharing activities (GOLD 2002, study).

Peter lives in a group home with three younger men but when he reached the age of 65 he was ‘retired’ from the day centre he had been attending for many years. The minibus still collects the other men each morning but Peter finds this very distressing. (Gold 2002)

Some older people with learning disabilities are placed in older people's residential services, not because of their own ageing but because of a change in circumstance, such as a closure of a service or a family carer's death. It is not uncommon for them to be much younger than the other residents and lack of support to engage in social activities affects their quality of life. The average cost of what is considered good quality residential support for younger people with learning disabilities is considerably higher than the average cost of a placement in an older people's care home (Thompson and Wright 2001, review).

Walker and Walker (1998, review) argue that ‘the artificial division between older disabled people and younger disabled people made by service providers is age discriminatory’. They examine the different principles behind service provision for these two groups: one has been based on a limited, age discriminatory view of ‘normal’ ageing, whereby disability is a natural part of ageing; the other has focused on a potentially liberating concept of supporting people towards a realisation of greater choice and independence. This difference in principles underpinning service provision for older

people and those with learning disabilities implies different forms and levels of service delivery and user rights (Walker et al 1996, study). Comparing the treatment of older and younger people with learning disabilities, they found that care workers made ageist assumptions towards older people with learning disabilities and as a result restricted the range of opportunities available to them even though they had been proved capable of gaining greater control over their own lives given the support to do so (Walker and Walker 1998).

In a study of all people with learning disabilities aged 65 years and over living in Leicestershire, England (n= 134), and a random sample of adults with learning disabilities aged between 20 and 64 years (n= 73) were assessed for psychiatric disorders and service use. Older people received less day care, less respite care, and were less likely to have a social worker and receive input from most health services than the younger group. Services were better accessed by those living in residential care. Failure to access services may relate to carers attitudes and beliefs: in learning disability settings, morbidity was attributed to 'it's just old age' in the settings for older people, morbidity was attributed to 'it's because s/he has learning disabilities' (Cooper 1997, study).

Summary

Older people with learning disabilities can receive poorer quality of services than younger people with learning disabilities after being referred to older people's services, and can be denied appropriate support services as a result of ageist practices. Older people's teams may have less to spend on care packages compared to learning disability teams.

17. Older prisoners

People aged 60 and over are now the fastest growing age group in the prison estate. In March 2008, there were 6,661 men and 316 women aged over 50 in prison in England and Wales, a total of 6,977; of these 2,300 prisoners were aged over 60 and this includes 454 people over the age of 70. The number of sentenced prisoners aged 60 and over rose by 149% between 1996 and 2006. The majority of men in prison aged 60 and over (56%) have committed sex offences. The next highest offence is violence against the person (20%) followed by drug offences (11%) (Prison Reform Trust 2008).

A review of older prisoners by HM Inspectorate of Prisons (2004) found little evidence that the individual needs of older prisoners were being assessed or provision made for them. It concluded 'Prisons are primarily designed for, and inhabited by, young and able-bodied people; and in general the needs of the old and infirm are not met.' There is evidence that social care needs are reportedly largely unmet and there have been difficulties experienced by older people with disabilities in obtaining equipment such as walking sticks or wheelchairs. Although the majority of prisons have

Disability Liaison Officers, prison staff report difficulty in establishing who has the duty to provide services (Prison Reform Trust/CPA 2003, study; DH 2008, policy document). The lack of a specific strategy for the care and management of older prisoners could be viewed as discriminatory (Ware 2009, review). The government is currently working on initiatives to provide care for older prisoners including wider use of the Single Assessment Process to enable holistic assessments of need.

Summary

There is evidence that social care needs of older prisoners are largely unmet as the majority of prisoners are young and able bodied. There have been difficulties experienced by older people with disabilities in obtaining equipment such as walking sticks or wheelchairs.

19. Conclusion

'Government policies designed to tackle age based discrimination have been extensive and are beginning to produce a cultural shift in perceptions of older people' (Phillipson and Scharf 2004, review). The culture of seeing older people as 'vulnerable' and needing protection, as problematic and burdensome, a group denied the ordinary things in life because of the process of ageing, has influenced the development of services for older people. 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. The disability movement has strongly influenced the ethos of support for younger adults with the concept of independent living that has only recently been extended to older disabled people.

19.1. Age discrimination in systems and structures

Social care services are explicitly organised around age and transition between services can be triggered by age rather than need. While there is an argument for providing specialist services to meet the particular needs of older people, the division between 18-64 adult services and 65+ older peoples services actually results in age differentiated services that can be discriminatory in a negative way.

An overarching theme is the low level of expectation by older people of what they will receive from services and providers of services limited views of what is acceptable to older people in terms of quality and choice compared to the population as a whole. Institutional ageism leads to an expectation by 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. Service responses need to be defined and driven more by older people to remove barriers created by other's expectations of how their lives should be lived.

The application of the Fair Access to Care Services guidance by many local authorities indirectly discriminates against older people. Services are being rationed through tighter eligibility criteria and generally restricted to a smaller proportion of people needing intensive care at home. 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. Despite a government policy of maintaining people in their own home, over the last five years, 2001-06, the shift of expenditure from residential care to community services has been relatively small. Compared to 2003, fewer older people per 1000 older population are receiving council arranged services in the community.

The boundaries between health and social care, and the division of means tested and non means tested services can lead to disjointed care and allegations of unfairness for older people. This is of particular concern for older people with dementia requiring care.

19.2. Age discrimination in policy and practice

Assessment is the gateway to support services. There is evidence that the focus and quality of assessments are different for older people compared with adults under 65 years. Social care services for older people are typically more concerned with physical needs and issues of safety than with enabling participation or inclusion and are as a result are more restricted than for younger disabled people in similar circumstances. The pressure on resources and professional assessment of risk can inhibit the development of person centred assessments for older people focusing on outcomes. There can be a lack of creative thinking about how best to devise a personalised plan for older people, taking into account their strengths as well as their needs. Inadequate assessment may fail to address individual needs like depression and sensory impairments that are put down to 'ageing' but require some social intervention and support. The quality of assessments is a particular issue for older people being discharged from hospital who might not be supported to make decisions about life changing issues such as going to live in a care home.

Younger adults with disabilities receive an additional aspect of help to enhance their quality of life and remain active within society, while older people's emotional and other broad quality of life needs are not being met under assessment which attend primarily to direct physical needs.

19.3. Age discrimination in resources and funding

There are institutionalised inequalities in the resources allocated between different groups of people who use social care services. The differential funding of care packages for older people and younger adults with disabilities is explicit. Pressure on resources locally is leading to tighter restrictions on services that benefit older people needing 'that bit of help'. Historically PSS [personal social services] expenditure per head on older people using social care services has been lower than for other adult client groups and there is evidence that at an individual person level, after controlling for needs and outcomes, the support (ie cost weighted service utilisation) received by older people is significantly less than the support received by younger people. Different cost ceilings applied to care packages for older people and younger adults with disabilities impacts on the support options available to each group. Markedly older people have a restricted range of opportunities particularly relating to social aspects of daily living. The widespread use of cost-ceilings equivalent to the cost of residential placement has limited the development of more innovative models of support and is an explicit example of direct age discrimination. Older people may have to accept going into residential care that is considered more cost effective for local authorities at an earlier point than younger adults.

Disability allowances are universal benefits but the differential access to funds based on age allows for greater flexibility and potential for innovative approaches to meeting support needs for younger disabled people compared to older people with disabilities. Attendance Allowance (AA) and Disability Living Allowance (DLA) are aged based with DLA allowing additional money for a 'mobility' component which is not available to older people with a disability. Disability Living Allowance is not available to people who become impaired after 65. People over 65 are not eligible to apply for support from Independent Living Funds but once they are in receipt of funds they may continue to receive them after 65.

19.4 Recommendation for further research

There is a need for further qualitative research around the assessment process and care management in social care to provide evidence of how the individual needs of older people can be met through more innovative and flexible use of resources.

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