

Notes from Workshop Two: 16th April 2013

Equality and inclusion: a question of rights and responsibilities

The aim of the workshop was to explore what “good ageing” is in relation to the law as it currently stands, whether we have a right to healthy ageing, and whose responsibility it is. A secondary aim was to identify and discuss possible challenges posed by a multi-cultural society for “good ageing”, including for the delivery of health and social care services, and political implications of ensuring inclusion and autonomy for an ethnically, culturally and religiously diverse ageing population.

Attending:

Claire Ball, Development Manager – Equalities & Human Rights Age UK; **Katherine Hill**, Policy Adviser – Equalities & Human Rights Age UK; **Professor Paul Knight**, President – British Geriatrics Society; **Professor Naina Patel**, Director – Policy Research Institute on Ageing and Ethnicity; **Dr Linda Patterson**, Clinical vice president – Royal College of Physicians

Discussions

These notes represent key points from the workshop

Professor Naina Patel, Director – Policy Research Institute on Ageing and Ethnicity

Professor Patel focussed on healthy and positive ageing and the past and future for research and policy in this area in particular relation to the ageing Black and Ethnic Minority population in the UK.

Key points

- There has been slow progress in ethnic minority health research. In 1998 when PRIAE was set up, BME elders were not on the policy agenda. BME elders were treated as one group in terms of their health and BME communities were thought of in terms of disadvantage
- Based on research conducted on organisations in London, Yorkshire and Scotland, PRIAE found that local projects rather than national health promotion strategies have promoted understanding about health in BME populations and about BME populations. These developments relied on voluntary and micro organisations working directly with populations. These were also a crucial resource for researchers.
 - In Birmingham, PRIAE’s film on dementia awareness ‘Dementia Matters’ has been used to increase BME referral rates on dementia
- A challenge for 2013 and health promotion in the future is how to sustain the BME organisations that form the bridge between policy and BME communities. The day to day funding of lunch clubs and micro organisations that arrange such activities is needed to encourage ‘active’ ageing, and yet most small organisations have had funding cut or removed.

5 factors were identified as important for health of BME groups:

- Effective information within care systems
- Good communication
- Full access to services
- Identity appropriate care (in terms of culture and faith)
- Hygiene and cleanliness of health services; Staff to be professional and behave with integrity

BME population and 'active' ageing

- BME elders are very engaged in health and health care, but barriers remain both to wider knowledge about the health of BME populations and also to the individual population's ability to access information and services supporting active and healthy old ages, particularly groups and organisations that consider needs of different faiths and cultures
- BME elders are not averse to change and health improvement, although are more concerned for the life chances of the young rather than about their own ageing and health in later life.
- Barriers to improved physical health and active ageing include motivation, information, language and culture.
 - Good information in accessible formats is needed for example PRIAE's 'Get Active Today' film which shows BME elders undertaking activities
- Family, peers and health professionals do not provide support and motivation for active ageing. There is an assumption by health services that family will provide care in BME communities but families are not always the best placed to encourage physical activity in their elderly relatives
- There is still a cultural view that elders should be less active but this idea is changing amongst particularly Chinese and Caribbean communities who access dance in particular as a way of socialising and exercising
- Community champions providing motivation and information could be a potential solution, to the challenge of sustaining health improvements in the long term

Emerging areas of competition within minority populations for public resources, particularly where those populations are concentrated and form a local majority, e.g. Leicester

Key messages: Practical funding support for organisations within communities, consistency of funding and support for research; community champions to provide examples as role models for active ageing as well as information for accessing services

A 'flamboyant' approach to ageing might stimulate positive ageing and progress

Professor Paul Knight - President, British Geriatrics Society

Key points from opening statement:

- When looking at 'positive' ageing, there is a need for a more balanced view in the debate around older people and ageing that on the one hand is viewed as a catastrophe and on the other hand is a really positive story of improved health and life chances – currently everybody over 65 is treated as one group by policymakers.

There are two aspects of the debate:

- The positive messages from WRVCS about the contributions of older people to society both economically and socially are at odds with the current government thinking about older people as a drain on resources.
- The 'other side' of the problems is the frail older population, often the very elderly, aged over 80 access to healthcare resource and care homes, with limited ability to access healthcare services normally available to the wider general population.

Health service delivery issues are related to the sheer numbers of older people:

- 2/3 of hospital beds are occupied by the 65+ age group and health services seem to still not be adapting to this shift in demographics of health service users.
- Older people need to be consulted about the construction of healthcare services to meet the growing demand; as the baby boomers move through the system they will demand service satisfaction, and their expectation of high quality care will drive change and service improvement (but this cannot be relied upon).

Dr Linda Patterson, Royal College of Physicians

Key points from opening statement:

- There is a challenge not just for policy but also practitioners around population understanding and medicine: Clinicians need to know the detail of their population and be aware of majority and minority BME groups which will challenge drive service delivery adaptations.
- People are living longer and this is a great success story; life expectancy at birth is now 12 years longer and people are more able, with many older people not accessing health care or hospital services at all in old age. However there are very real challenges related to ageing:
- From a health perspective, the issue of ageing is about management of long term conditions. There are a rising number of people with long term complex, interactive conditions, and over half of people aged over 60 have at least one long term condition. Frailty and dementia are key challenges. Frailty is a syndrome of ageing and dementia is a key challenge, with 30% of people over 80 have some cognitive impairment
- Hospital inpatient demography has changed dramatically since the creation of the NHS. People come into hospital older, frailer and having more than one condition, perhaps including dementia. People over 65 occupy over 70% of beds in hospital, although patterns

of admissions, age profiles and lengths of stay are different in age groups 65-75, 75 – 80 and 85+, for example over 85 tend to spend 8 days on average longer than those aged over 65 in hospital.

- Despite this, the reaction of hospital services and clinicians' attitudes has not kept up with changing hospital populations. Older people are still treated as a problem in hospital rather than a key demographic.
- A lot of single interventions in the community had not had any effect on reducing hospital admissions and we may need to try multi-faceted interventions to get any reduction. The aim of reducing admissions is not an end in itself; people need to be treated at the right time in the right place for their needs. We need to be moving towards developing better community services but also acknowledge that older people do need to come into hospital – but their stays should be shorter which produces better outcomes. That needs joined up care with community services, social care and the voluntary sector.

Discussions reflected 4 broad themes in relation to ageing and health: Integration of care, training needs, ageing and rights and frailty.

Hospitals and integration of health and social care theme

The RCP has a 'Future Hospitals' Commission process that is reporting in summer 2013

- Practise within hospitals in relation to the admission, treatment and discharge of older people needs to change, due to the increasing age demographic and the increasing numbers of old people. There are failures around discharging older people as well as good schemes to assess the needs of older people at the front doors of hospitals. More can be done to prevent admissions and re-admissions and to shorten the length of stay, and there is some evidence that areas with integrated services may have lower admission rates. However those with acute conditions will need to be admitted and hospitals have a responsibility to meet their health needs
- Multifaceted interventions aimed at keeping people well at home are important, however keeping older people out of hospitals is potentially ageist; by keeping people out of hospital are they being denied access to high quality healthcare
- The Francis Report showed that a lot of the patients receiving poor care were more elderly. Holistic care for the elderly matters: Ward level care needs to support dignity and poor standards of care should be met with a zero tolerance attitude
- Older people must have equal access to safe, high quality care and Hospitals, as well as the medical staff, must adapt to ensure they are meeting the health needs of older people particularly those who are frail.
 - [Michael Dixon](#) article in independent 'Hospitals must shrink or shut'

Training

- A BGS survey of 30 medical schools in the UK showed that only 17 have structured programmes around ageing within the training schemes. However all clinicians will work with older people in their careers unless paediatrician or obstetricians
- Need more specialist doctors but also an understanding that individual specialists may not be best placed to treat the syndrome of frailty, and older people with multiple illnesses. The

need is for more consultants with more generalist skills and enhanced skills in dealing with older people

Frailty

- The media gives impression that older people need basic care but in fact older people's care is quite complex
- Nobody wants to be labelled as 'old' or 'frail' and this is a particular issue for western cultures that 'geriatric' is a pejorative label, perhaps because you don't grow beyond geriatric.
- A clear definition of frailty and its treatment needs to be agreed; whilst age demographic will change over time, the concept and treatment of frailty would be broadly similar across groups. Evidence suggests that the condition of frailty requires a proper clinical and treatment focused on the condition for a better clinical outcome
- Treatment of diseases needs not just to look at a disease but also at the restoration of function which promotes independence.
 - Mary Todd ['The end of the Disease Era'](#)

Ageism

- Everyone is surprised at the reality of volumes of older people in the health care system and some staff are un-trained or unsure how to cope, and perhaps resent the presence of older people in wards.
- Ageing is included in the English NHS constitution which enshrines a duty to individuals to respect human rights and promote equality in services. This is related to the public sector legal duties of equality and non-discrimination (race, gender and faith). Discussions reflected that the NHS is potentially discriminatory to elderly both in language and activity.
- Obvious discrimination has been reduced and services for the elderly have been improved and treatment today is much better and more equal for older people
- There remains an inherent indirect ageism around older people in hospital by medical and nursing staff which affects the health and recovery of older people who are receiving treatment in hospital. The Francis report shows how older people were badly affected by poor quality hospital care
 - Dr Win Tadd's research on dignity in care of older people ([link](#))

Claire Ball, Development Manager – Equalities & Human Rights Age UK

Katherine Hill, Policy Adviser – Equalities & Human Rights Age UK

Key points from opening statement

Equality and Human Rights framework lens at what the tools in this has to offer in support of a paradigm shift for ageing well. The focus is on the Commission's questions 'Do we have a right to healthy ageing?' and 'whose responsibility is it?'

There ought to be a right to healthy ageing and the key agenda would be to make this right more realisable:

- The Human Rights Act has limits; for example Article 2 of the HRA made the Francis enquiry possible. In the final report, however, the recommendations and solutions are not made in rights-based language. The report takes questions about dignity and respect but does not talk about them as a matter of potential illegality.
- We have a human rights framework for the NHS and patients should use the NHS constitution to further their rights. This could provide a framework for a paradigm shift, to make abstract human rights seem relevant to individual.
- Equality is a core principle of human rights. Older people need equal rights and need to be able to enjoy their rights equally.
- Obvious barriers have diminished but discrimination is still present in attitudes of individuals. The ban on age discrimination is helpful, however it continues to exist within health treatment.
- Rights aren't contingent on responsibilities and we must avoid shifting responsibility on to older people for their health. For example death rates from CHD graph (slide 4 of presentation - <http://www.birmingham.ac.uk/Documents/research/policycommission/BPCIII-AgeUK.pdf>) shows that more than half of improvement in treatment is due to risk factor reduction (changing behaviours) as opposed to improvement in medical treatment. This does not mean that all responsibilities for health should be placed on shoulders of older people. It depends also on people's ability to take responsibility for their health.
- The private sector should also have a responsibility for enabling good health behaviours, for example in providing options for exercise; gyms are often not aimed at older people and their image may put older people off using them.

Health and Social Care Act 2012

Although it is too early for real impact measurement, Age UK is concerned about service performance and the needs of older people being met in the period of reform. The Act holds the potential in terms of a framework for local people to define what is suitable for their local situation. Local services and GP commissioning can focus more closely on particular unique mix of needs, to allow a more granular view of local needs and priorities.

- There is still inherent ageism built into the Health and Social Care act
- Private sector commissioning within the NHS may impact on the commissioning of services for the elderly
- Health and Wellbeing Boards play a role in commissioning and giving a local image of the needs of local areas. Bringing public health, housing, sport and leisure together, enables a focus on the place and ensure the potential of the act is realised
- The potential of Human Rights and Equality acts could be in their use as a key framework for advancing rights to healthy ageing and the legal duty is the tool to make sure it happens.

Learning from experience and practice: Claire Ball, Policy Advisor, Age UK

Age UK described examples from experience and practice built at a local project level from Age UK partners working with BME communities, highlighting opportunities related to health promotion programme, in relation to the question about 'whose responsibility' is it to promote healthy ageing:

- Age UK's experience of project delivery is that it is the responsibility of a series of actors who share responsibilities for health promotion but resources tend to be at a project level.
- 'Fit as a Fiddle' in partnership with Sporting Equals focussed on promoting healthy eating, physical activity and mental wellbeing for older people from BME communities to confront key issues of heart disease, diabetes and stroke.
 - Social isolation: [Age UK mental health: a guide for professionals](#)
- The programme demonstrated that it is important to work in partnership work across agencies, for example Sports centres reduced costs and increased participation in their activities.
- In terms of shared responsibilities, the programme highlights the important of working in partnership across agencies, for example participating leisure centres lowering fees and increasing participation.
- 39 local partner organisations in BME communities were involved and trained volunteers enabled a degree of sustainability (related to the Champion roles from PRIAE's support)

Discussions contributed the following points:

- Commission may look at key differences in the experience of discrimination in majority/minority elders. BME elders will have more indirect discrimination examples particularly related to the migrant experience of ageing. As a result, elders don't go elsewhere; they simply don't use services, contributing to a decline in demand
- Social Class and the concentration of poverty across all communities has health implications Particular communities face serious issues of equality, for example 70 is extremely old for the gypsy and traveller community.
- The character of patient base in terms of age and ethnicity is important. Britain has been multicultural for a long time and cultures are in constant flux; Polish elders wanted to have more of a genuine Polish link, whereas the elderly Jewish feel that their Jewish recent immigrant carers did not understand their own identity that was formed in the UK.
- Many BME care homes have a globalised workforce, and the majority white elders are having their personal care provided by an extremely diverse ethnic minority health workforce working closely with them.