Notes from Workshop Two: 16th April 2013 (afternoon)

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.

Ann Gallagher, Reader in Nursing Ethics – University of Surrey, Director – International Centre for Nursing Ethics**; Professor Jonathan Montgomery,** Professor of Healthcare Law – Southampton University, Chair – Nuffield Council on Bioethics; **Professor Chris Newdick**, Professor of Health Law – University of Reading; **Stewart Sutherland,** Royal Commission on Long Term Care of the Elderly 1997-99, Lord Sutherland of Houndwood

These notes represent key points from the workshop

Professor Chris Newdick, Professor of Health Law – University of Reading

Key points from opening statement and discussions:

- We have not fully recognised the economic cost of ageing going into the future NHS. Present trends predict disproportionate spending on lifestyle illnesses and ageing within the context of longer term health conditions and a very specific drain on resources.
  The Office for Budget Responsibility says there is a risk of the NHS becoming "unsustainable." We should change now to ensure the future sustainability of the service

Health maintenance and improvement behaviours

- The 'autonomy' model of individual choice makes changing people's lifestyle choices challenging, particularly when already living a culture or lifestyle that will drive towards ill health
- Investment in promoting healthy lifestyles should be targeted at younger generations to try to change behaviour as an investment in the future, both for public health and the future sustainability of the NHS.
- This is consistent with the Marmot Review and the links it makes between inequality and health

Where should that debate on behaviour change and responsibility for health take place?

- Amartya Sen in 'The Idea of Justice' (2009) suggests that it is the responsibility of government. Disproportionate emphasis on individual behaviour, without commensurate undertakings from government, would be unreasonable.

- The State has a duty to its citizens. But this includes a duty to the future generations as well as the citizens of today. Edmund Burke recognised this 200 years ago and made the point about the duties of citizens to future generations.
- The NHS Constitution covers equality in care for all citizens but does not recognise the challenges posed to the NHS.

Integration and collaboration

- Health service co-ordination with broader services is crucial. Provisions in the Health and Social Care Act place duties on public bodies such as Monitor and NHS England to tackle inequality. It will be crucial for public health to find its "voice" and for statutory responsibilities to be divided clearly between the NHS and local authorities.
- Government and health campaigns have focused on specific illness conditions, eg obesity and heart disease. But these diseases tend to cluster amongst patients in the same social groups and more broad-ranging campaigns may be more effective.
- Assuming additional revenue is not available, the ambition to improve long-term health and to close inequality gap is likely to be at the cost of exiting expenditure requirements. This is a significant challenge.
- There is potential for collaboration between local authorities and the NHS, to start a different form of service provided for young families in particular, for a larger future return. However, NHS and LA services have had a right to integrate before but it did not happen. Integration needs a specific steer from government.
- Government interest in "Nudge" policies deserves further research. Equally, the banning of smoking in public places goes beyond "nudge." We also need to consider when Interventions of this more robust nature are also publicly acceptable.

Ann Gallagher, Reader in Nursing Ethics – University of Surrey, Director – International Centre for Nursing Ethics

Focussing on questions 1, 3 and 5 of the workshop, the following points were made in the opening statement and in the discussion that followed:

Question 1: Do we have a right to "healthy ageing"?

Considering the concepts of health, ageing and rights, understanding what we mean by 'health' is important Fuller definitions are provided in the supporting submission to the Commission:

- The WHO defines ageing is an opportunity rather than a burden
- Europe is focussed on optimising opportunities for good health
- Ageing can be 'good' but not healthy, i.e. can be high quality despite mental deterioration and living with long term illnesses, or dependency on others

Important to understanding 'experience'

- Understanding experience is important for professional practice, care and ethics and education in health and healthcare.
- The media portray the experience of ageing in particular ways: In the arts films such as Isis, Iron Lady, Amore, Quartet and Best Exotic Marigold Hotel have an impact on how the public perceive ageing
    - Alistair Macintyre work on 'Dependent Rational Animals'
    - 'Nothing older than not wanting to grow old'
- Media often tells negative stories (Francis Report and failures of care).

Question 3: *Whose* responsibility is/ should be to promote/ensure/facilitate healthy ageing in a multi-cultural society?

- NI Human Rights Commission focussed on issues of everyday care within a human rights framework
- Rights based practise covers a statement of certain minimal and enforceable rules that communities must live up to
- It would be wrong to link rights to healthcare directly to responsibilities in a health practise sense. People are fallible and vulnerable and poor health choices are not always under our control
- Focus should be on relationships between people, care services and professionals, and professional leadership (Francis report) with clear processes for escalating concerns

Question 5: What are the major challenges for the delivery of health and social care services for an ageing population in a multicultural/multi-faith society today?

- The NHS management language of targets (flow and throughput) is not a good fit with ageing and older people
- There is a challenge presented by the diversity of older people and also of the health care workforce
- Francis Reports and Patient Association identify older people at high risk of neglect in the care system and hospital

Evidence related to ethics and healthcare is presented in Ann's paper in greater detail, however a Social care ethics project to explore what enables ethical practices was mentioned which explored the importance empathy and stories (personal narratives) which linked to the Theme 1 evidence from the FCMAP project.

There are many professional values and legal rights frameworks, but they are not widely used by patients and staff to enforce their rights.

Pay and dignity of the worker is central to dignity in care – many workers in care context are paid little and are expected to take great responsibility and is important for dignity and wellbeing of both patients and workers that they are valued.

Groups called 'the elderly' but is a hugely diverse group of people of many ages

A key point was about asserting rights around how to define 'old' or just unwell. Should older people as a group have a set of rights:

- There is a difference between an older human being and a frail human being
- 'Age' is an objective way to assess and apply rights. Frailty is more open to interpretation.
- Our picture of a normal human being is self asserting, but an alternative starting point could be to ask what makes an 'adequate' human life; an alternative human life that is different to the individual.

Ageism and the NHS in terms of decision making

- GPs and Commissioning bodies are now required to make difficult decisions on funding of drugs and procedures in relation to particular groups
- Decisions are made about treatment but this would be based on clinical factors. Difference in treatments as to whether it is 'ageist' would depend on the rationale and justification for the decision
- Individual GP makes decisions on a vast array of variables and factors so there is a need to have better ethical guidance on decision making
- There is evidence of indirect discrimination in the NHS. The structure of hospitals ends up disadvantaging the elderly even though they for the majority of patients

Professor Jonathan Montgomery, Professor of Healthcare Law – Southampton University, Chair – Nuffield Council on Bioethics

Key points from opening statement

- A key aspect of the problem is understanding whether the problem is 'ageing' or the 'NHS services' in relation to institutional discrimination in the NHS
- We have a flow diagram system of care in hospitals wastes resources: If everyone was in the correct system to treat them resources would be sufficient. The problem is that people are moved around until they finally arrive at the correct place, rather than going directly to the correct Unit (e.g. stroke unit)
- Characterising the nature of the problem as a 'problem of ageing' or a 'problem of poor quality services' If hospitals worked better this may solve the problem of increased numbers of older people using the system.
- We must avoid stigmatising 'age'. It is something about frailty rather than age itself that comes into play when understanding age and health
- The stronger a duty, the more enforceable it must be and it must have a trigger. Age is more objective than frailty as a trigger for obligations. Age already triggers certain rights such as free bus pass and winter heating allowance.
- Constitution is about aspirations and the detailed handbook provides details about obligations. The NHS Constitution raises the profile of rights and obligations and should make the delivery of rights more effective. Rights to health and rights to life are in international literature – but it is hard to enforce idea of rights

- A champion for the elderly would provide a focal point for pushing an agenda for ageing populations. This could be provided by a Commissioner for older people (as in Wales), or a local champion for older people's rights

Targets:

- Targets change behaviours by changing relative proprieties of people – but targets need to be temporary, or else they create problems, as in Mid Staffordshire.
- Rights are similar: they are formulated in relation to other things and assume a relative importance

Control, autonomy and public health agenda

- Individuals who 'lose control' of their health may 'regain' autonomy and control through health treatment
- Interventions may be 'nudges' and encouragement or through stronger more paternalistic responses. The Nuffield Council report produced the intervention ladder to explore interventions and choices
- In Nuffield Dementia report found that what really matters is the quality of relationships, what really need in as people move towards being more dependent on others
- Rights of healthy ageing include rights for carers, as are the duties that carers have towards patients. These re-enforce the legal duties on institutions to provide care.

Stewart Sutherland, Royal Commission on Long Term Care of the Elderly 1997-99, Lord Sutherland of Houndwood

Key points from opening statement and subsequent discussions

- The NHS is successful in its role to provide health care. Advances in public health and medicine have produced a situation that more people live a reasonably good quality of life than ever in history. This is happening even in 'underdeveloped' countries.
- This progress has produced unprecedented questions in relation to growing and longer lived populations. In a shortened resources situation, longer life and fewer resources pull against each other
- We need long term thinking about the physical and social structures in which we live including housing, transport and pensions systems. Patterns of work are also unsuited to modern life cycles, although increasingly people are working longer simply because they have more life ahead of them
    - Transport is extremely valuable to older people but universal system of free travel could be managed more equally, for example by giving a prepaid card that allows cash to be spent on taxis (for example in rural areas where buses aren't available).

General discussion followed around the integration of services:

- National and local Health services have to come together. Doctors and social work partners are each protecting budgets and in conflict. Integration won't resolve conflicts but there are pilot studies out there including in Scotland.
- Integration can often be a secondary aim of local authorities, with proprieties being outcomes.
    - Care infrastructure can be improved to help integration: Scotland has one central record for patients.
    - Bed blocking is an issue and better discharge procedures into the community are important
- One of the traps of integration is the very broad network of services that people rely. Universal services (libraries, parks, leisure centre) are important, and profit based organisations also operate and the risk of integration may solidify a service but one that doesn't have a great deal of choice.
- Inequalities in communities are important as the same communities face deficits in housing, education, and income quality. In communities, what can work is a single point of contact(often a GP), a single assessment, and a single point of commissioning

A Commissioner for older people

- The role of GPs was discussed around whether a Commissioner would be helpful in how it could point out problems and pick up causes for patients and care systems. Clinicians should maintain a purely clinical relationship, rather than using their authority to influence resource allocations which would be the role of a 'champion'
- Enshrining rights in law may lead to a temptation for people to go to the law to demand their rights
- Any Commission or commissioner carrying national or local responsibility to safeguard and promote rights would have to have a duty to do so. Need to have power to pick up issues relating to older people particularly.
- Health and Wellbeing Boards could also be asked what they are doing to progressively realise a commitment to healthy ageing

System questions

- System that doesn't work for some people because they aren't able to exploit the system that is currently available, for example accessing transport systems.
- Around questions of discrimination, it is not necessarily that the system is discriminating, but rather that the system that is not performing or responding adequately to needs
- In terms of social capital, faith organisations may have a role in helping economically disadvantaged communities access services
- Social capital can contribute to inequalities, in the sense that having more social capital increases your ability to protect your assets and rights, particularly in relation to the cost of care.