Birmingham Policy Commission

Healthy Ageing in the 21st Century

1. Do we have a right to "healthy ageing"? Is this affected by our obligations under the Human Rights Act 1998 and indeed should it be? What responsibilities do/should older people have?

We need to ask what we mean by 'healthy' - or 'good' – ageing? The WHO (1948) definition is: 'a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity'

Appears to set an impossibly high bar – would any of us qualify as healthy on this account? EuroHealthNet offer a helpful definition of 'healthy ageing' – 'optimising opportunities for good health, so that older people can take an active part in society and enjoy an independent and high quality of life' – treating ageing as an opportunity rather than as a burden – an 'assets-based approach'. Creating the right conditions for healthy behaviours with opportunities for meaningful activity, good diet, fulfilling social relations and 'financial security' (see http://www.healthyageing.eu/)….It is possible to envisage a life that involves dependence but is still of a high quality.

Perhaps we need to look to different literature and media to fully grasp the reality and possibilities of healthy/good ageing and to engage with our own ageing?: Can ageing be 'good' but not 'healthy'? 'Good' despite mental deterioration? Good in that the older person is loved, cared for, comforted and respected but with health deficits, lacking the capacity or opportunity for 'meaningful activity' and dependent? I am reminded of Alasdair MacIntyre's *Dependent Rational Animals: Why human beings need the virtues* (1999). There are also helpful perspectives in Lesser's (2012) *Justice for Older People*. A non-academic book that offers interesting insights is Marie de Hennezel's (2008) '*The Warmth of the Heart prevents your Body from Rusting: Ageing without growing old*'. She states:

> 'there is nothing older than not wanting to grow old. We are afraid of dying badly, alone, unloved, perhaps dependent or suffering from dementia…The worst is not inevitable. Something within us does not grow old. I shall call it the heart, the capacity to love and to desire, that inexplicable, incomprehensible force which keeps the human being alive…'

Perhaps also engaging with film narratives such as: Iris, Amour, the Iron Lady, Quartet, Best Exotic Marigold Hotel. We might also draw attention to the positive role of the Elders (see http://www.theelders.org/).

Regarding rights - consider the requirements of negative rights (freedom from torture/indignity, for example) and the limits (if any) of positive rights. We might also consider the adequacy of rights discourse in relation to

healthcare…Beauchamp & Childress, for example, stated that a rights-approach is:

> 'not a complete moral theory, but rather as statement of certain minimal and enforceable rules that communities and individuals must observe in their treatment of persons'.

And can a right be claimed to this ideal state? Gostin and Lazzarini (1997 Human rights and public health in the AIDs pandemic) state:

> 'A right to health that is too broadly defined lacks clear content and is less likely to have any meaningful impact [rather it may be regarded as…] the duty of the state within the limits of its available resources to ensure the conditions necessary for the health of individuals and populations'.

They argue that many factors that impact on health are beyond the control of government e.g. genetics, behaviour, climate and over-population (McHale and Gallagher 2003). Article 25 of UDHR states:

> 'Everyone has a the right to a standard of living adequate for the health and wellbeing of himself and his family including food, clothing, housing and medical care and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control'.

See International Council of Nurses (2009) statement re rights and health (see http://www.icn.ch/images/stories/documents/publications/fact_sheets/10b_FS-Health_Human_Rights.pdf)

See also Northern Ireland Human Rights Commission work re human rights, older people and nursing homes (http://www.nihrc.org/documents/research-and-investigations/older-people/in-defence-of-dignity-investigation-report-March-2012.pdf) - this work has particular value as it integrates human rights, legal background and also practical aspects of care e.g. personal care, eating and drinking, medication and health care, restraint. There is also a large nursing ethics literature on dignity – see http://nej.sagepub.com/ and http://www.rcn.org.uk/__data/assets/pdf_file/0011/166655/003257.pdf

Regarding the responsibilities of older people – this is challenging as may result in initiatives distinguishing between deserving and undeserving. Persons are fallible and vulnerable and poor health choices are not always under their control. Perhaps if we enshrined these responsibilities throughout our educational system under the umbrella of good citizenship and solidarity?….however, we should be wary of supporting initiatives that link rights to responsibilities thus disadvantaging those who are unable to adhere to health education initiatives etc.

It is suggested that the discourse of rights and responsibilities is supplemented by other approaches e.g. virtue ethics or ethics of care.

2. How do we balance the rights of different generations (particularly with all the challenges current young people face in the current economic climate)?

Unsure. Education would seem to have a role in breaking down inter-generational barriers and in promoting positive ageing perspectives. One care home I know of, for example, worked with a local primary school to identify a name for the care home.

3. Whose responsibility is/ should be to promote/ensure/facilitate healthy ageing in a multicultural society? All of us?

4. Is ageing inevitably a factor for social exclusion? No. But much more work required to develop inter-generational understanding and to challenge negative stereotypes of ageing.

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? - Resources, multi-pathology including dementia, speed of 'flow'/'throughput', diversity of older patients and care workers and reports from Francis, Patients' Association, Health Service Ombudsman & CQC identify older people as group particularly vulnerable to neglect/care deficits.

Evidence/what do we know about health and social care issues and older people? Research examples – We are currently working on a project (CHOICE) with a local Trust relating to end of life care choices for older people. The aim is to help care home staff to develop confidence and competence in end of life care so that older people can end their lives in a preferred place rather than being brought to hospital by ambulance unnecessarily. We hosted a Social care ethics conference on 12/04/13 (a collaboration between University of Surrey and Ethox). This was a precursor to a 6 months scoping project. Questions explored included:

What enables ethical/good care practices in social care for older people? (training, knowledge of special needs of older people, empathy, focus on experience and stories, role modelling, invest in good leadership, clear process of escalating concerns, reward good practice etc);

The role of regulators (prosecute for corporate manslaughter, be proactive, unannounced visits, role of professional codes? etc);

How to develop a positive working relationship with the media (e.g. trust each other, professional responsibility, service user involvement, PR work needed with perhaps education role, be proactive in providing information to media, be honest, not defensive, work with local media etc);

Research questions to explore? (what works? what are the barriers? how to disseminate most effectively? different issues for different care contexts (eg care home Vs domiciliary care)? impact of culture on good/ethical practice? how should care staff negotiate dilemmas relating to, for example, personal identify? do we need a different ethics for social care? etc)

What we know from research published in *Nursing Ethics*?

See Suhonen et al (2010) Research on ethics in nursing care for older people: a literature review in *Nursing Ethics* 17(3) pp.337-352. **Research topics** include: Older patients' perceptions of Compassion Van der Cingel; Decision-making about resuscitation Godkin and Toth; Ethically problematic situations in LTC Teeri et al.; Levels of loneliness, boredom and helplessness Bergman-Evans; Lived experience of grieving a loss Pilkington; Meal situations, ability to eat and fluid intake Sidenvall and Ek,Sidenvall et al. and Wu et al.; Need for community-based LTC Krothe; Preferences of resident and being listened to McFarland, Jonas-Simpson et al.and Shin; Problem of hearing impairment and listening environment Tolson and McIntosh; Quality of life and living in a care facility Oleson et al.,Byrne and MacLean,Fiveash and Heliker and Scholler-Jaquish; Quality of care, caring activities, care facilities,competence and care giving Grant et al.,Pincombe et al.,Heliker, Ballantyne et al., Marini, Roe et al., Chi et al., Mossop and Wilkinson, Oh, Coughlan and Ward, Demiris et al. and Kawamura et al.; Relationships, interactions, social engagement and communication McGilton et al., McGilton et al., Gerritsen et al., Brown Wilson, Van Beek et al. and Simmons et al.; Self-management Wilson et al.; Spirituality and spiritual care Wallace and O'Shea; Therapeutic environments, environmental factors' effect on patient symptoms Edvarsson, Voyer et al. and Wang et al.; Disruptive behaviours and use of medication Voyer et al.69 etc.

Other topics in Nursing Ethics literature include: truth-telling in dementia care; dignity in care (older person and care worker perspectives); end of life issues; informed consent; and elder abuse and mistreatment. **It is important to consider the experience, dignity and human rights of care workers as well as older people receiving services. Care workers are generally poorly paid, offered little training and work in a sector that is not adequately valued despite the importance of the work.**

6. What if any will be the impact of the reforms contained in the Health and Social Care Act 2012? Unsure as yet although it is suggested people will have more choice.

7. What will be the implications of the Equality Act 2010 for the delivery of health and social care services to an ageing and increasingly multi-cultural, multi-faith population? Unsure. Perhaps if there were some high profile case challenging ageism this could have a beneficial impact?

8. To what extent are rights and responsibilities in relation to healthy ageing an inherently gendered issue? See ICN statement and section in NI Human Rights Commission work re human rights, older people and nursing homes (http://www.nihrc.org/documents/research-and-investigations/older-people/in-defence-of-dignity-investigation-report-March-2012.pdf) - p.17-18.

9. Do we need a UN Convention on the Rights of the Older Person? Perhaps. What impact have other rights conventions had on particular groups (children for example?)? This would also have be considered in the context of a raft of codes, declarations and charters – perhaps having a commissioner would raise the profile?

10. To what extent will the involvement of the EU in relation to ageing law and policy become an important driver for change in this area in the future? What challenges might such involvement bring? Unsure.

Final thought – Perhaps we should consider that a very positive aspect of healthy ageing is to be able give thought to and prepare for later ageing, for example the potential transition to frailty? Health professionals are well placed to initiative conversations about later life and to encourage people to prepare, perhaps completing an advanced care plan (albeit in a broader sense). In clinical ethics committees, very common challenges arise - relating to the care of older people – when there is conflict between family members and sometimes also professionals regarding the best interests of a person who does not have capacity. If there had been prior conversations, this could be avoided. Health professionals would also then be in a good position to advocate for the older person and to minimise paternalistic approaches.

Ann Gallagher - a.gallagher@surrey.ac.uk