

United Nations Open-ended Working Group on Ageing

Fifth working session

New York, 30 July -- 1 August 2014

Panel on Planning for End of Life Care – Legal and Financial Issues

31 July 2014

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A. INTRODUCTION

I am very grateful for the invitation to participate in this panel. While I do so in my individual capacity, I should note that I also serve as an adviser to the Asia Pacific Forum of National Human Rights Institutions. The Forum consists of 15 full and 6 associate members from the Asia Pacific Region and has submitted a written statement to the Working Group expressing its support for the elaboration of a new convention.¹ It is a procedural curiosity that national human rights institutions are not invited as a matter of course to take part as formal participants in these sessions, as they are in various United Nations human rights bodies including the Human Rights Council. This is all the more anomalous, given the role they played in the negotiations on the Convention on the Rights of Persons with Disabilities and the explicit recognition in article 33 of that treaty of their special role in its implementation.²

My task today is to address issues relating to end of life care issues, with a focus on legal and financial issues. My comments are those of an international human rights lawyer rather than someone with special expertise in relation to elder law or ageing issues. I

¹ The Statement appears at the end of this paper. The Statements made by NHRIs and their regional groupings do not appear on the website of the OEWG. The heading designated '[Statements to the Fifth Session: Statements by National Human Rights Institutes](#) [sic]', which was on the OEWG website at the commencement of the Fifth session of the OEWG had been removed from the OEWG [website](#) by 7 August 2014 and does not appear on the current version of the website (<http://social.un.org/ageing-working-group/fifthsession.shtml>).

² See Maya Sabatello and Marianne Schulze (eds), *Human Rights and Disability Advocacy* (University of Pennsylvania Press, 2014).

propose to mention a number of issues which have emerged as important in the Australian discussions about ageing in the end of life context, as well as in comparable countries. I am aware that my selection of issues reflects a particular national and personal perspective and that some of the issues may be of greater current relevance in developed countries. But there are also common issues in these areas, as the presentations by my colleagues on this panel make clear.

I will then offer some reflections on how a treaty that addresses the human rights of older persons might be expected to engage (or not) with these issues. And I will conclude with some comments about what steps are needed to help address these issues and others, and why this Working Group needs to move to the next stage of its work, the elaboration of the new convention.

B. END OF LIFE ISSUES

It is difficult to limit a discussion of end of life issues to a narrow compass, as some of the issues are linked with ageing more generally – the recognition and exercise of legal capacity and ageist stereotypes about the decision-making ability of older persons is one example of this link. Other issues with human rights implications relating to the end of life can best, or indeed only be addressed before a person enters what one understand as the ‘end of life’ stage of their life – examples are enduring powers of attorney, financial arrangements to ensure adequate residential or other forms of care and support as one ages, and advanced care directives.

I will touch on three end-of-life issues that have received recent attention

- Decisions about the timing and manner of one’s death
- Legal capacity issues
- Discrimination against lesbian, gay, transgendered or intersex (LGBTI) older persons

Decisions about the timing and manner of one’s death

Perhaps the most important of all end of life issues is the right of a person to have control over the manner and timing of their death, in particular when suffering from a terminal illness. The right to exercise one’s autonomy and the right to die with dignity, are part of this discussion. This is a sensitive and contentious topic, but nonetheless it needs to be addressed.

There are a number of different aspects of this issue. One dimension is the pre-emptive perspective, where a person indicates in advance what forms of medical treatment he does not wish to have administered if he is unable to indicate his wishes as the result of illness. This has been dealt with in Australia, as in many other countries, by way of advance care directives, which seek to ensure that the person's wishes are respected at the later time. In Australia, if the formalities provided for under federal or State law are complied with, an advanced care directive may be legally binding, and a failure by health professionals to comply with it may lead to the imposition of civil or criminal liability on the health professional. Complications can arise where the requisite legal formalities are not satisfied, where there has been a substitute decision-maker appointed (guardian) who may take a different view from that expressed in the advanced care directive; and where cultural expectations about who should be involved in end of life decisions do not sit well with the notion of an individual's decision expressed through an advanced care directive. And this is only in relation to that subgroup of society that actually executes such instruments; for some communities they may be seen as culturally or otherwise inappropriate.

A further dimension is the question of a right to pain relief when suffering from a terminal illness, a topic addressed in one side-event during this session of the Working Group.

A vexed question is the extent to which a person suffering from a terminal illness has a right to assistance in bringing an end to his or her life. This issue has been the subject of a number of prominent cases in recent years in the common law world – including an important judgment delivered only a month ago by the United Kingdom Supreme Court³ – as well as a series of cases before the European Court of Human Rights.⁴ Some of these cases involved persons who suffered from degenerative diseases or other diseases which in the person's view rendered their life intolerable. The persons involved sought to have the assistance of others in ending their lives or at least to have clarified whether a person who provided such assistance would be subject to criminal prosecution.

The international human rights jurisprudence reflects the reluctance of the drafters of international human rights treaties and their judicial interpreters to reach definitive

³ *R (on the application of Nicklinson and another) (Appellants) v Ministry of Justice (Respondent); R (on the application of AM) (AP) (Respondent) v The Director of Public Prosecutions (Appellant)* [2014] UKSC 38 (25 June 2014).

⁴ These cases are reviewed in the various judgments in *Nicklinson* [2014] UKSC 38.

conclusions on whether international law guarantees the right of an individual to end his or her own life, and to receive assistance to do so, either generally or where the person is terminally ill and unable to take actions him- or herself. International human rights law neither explicitly guarantees a right to assisted dying nor does it prohibit this provided adequate safeguards are in place – the substantive issue is left to the decision of national authorities.

These issues have been explored in the cases I have referred to within the context of the general human rights guarantees, in particular the rights to life and the right to respect for one's private life, which were not formulated to address these issues in a detailed way. It may be that it would not be possible during the drafting of a new convention to reach agreement on whether a right to die (or a right to die with dignity) is or should be guaranteed by international law and, if so, what those rights mean. However, an explicit discussion of these issues, including the right to pain relief and palliative care in that context, might lead to the inclusion of articles on this issue in a new convention.

Legal capacity

We all know that increasing age may bring with it limitations on a person's capacity, though often one also sees stereotyped assumptions about the decline in an older person's ability to exercise legal capacity and the sidelining of the individual's wishes because of those assumptions, rather than an actual lack of legal capacity. However, the question of how one identifies and addresses the issue of reduced capacity is a recurrent one in Australia and in many other countries.⁵ The question was and continues to be one of the most contested in the context of the Convention on the Rights of Persons with Disabilities (CRPD), in particular whether that Convention (which embraces supported rather than substitute decision-making) ever permits substituted decision-making.

If the variety of national laws and experiences on legal capacity that emerged during the drafting of the CRPD are any indication, both within and across countries there is a range of practices, some of which appear to be at odds with the fundamental principles of the CRPD, insofar as that treaty applies to older persons.

In the present context one of the issues that needs further exploration is whether the approach taken under article 12 of the CRPD and in the practice of the Committee on

⁵ See, eg, Australian Human Rights Commission, *Respect and choice – A human rights approach for ageing and health* (2012) 16-17.

the Rights of Persons with Disabilities is the standard that should apply in relation to older persons when issues of legal capacity arise. Is the way set out by that Committee in its recent General comment on article 2 of the CRPD,⁶ which deals with legal capacity, or is a different approach needed that builds on the CRPD but reflects other experiences as well?⁷

Discrimination against LGBTI persons

Another human rights dimension in the end of life context – which also has a broader relevance – is discrimination against lesbian, gay, bisexual, or intersex persons. In some countries the law fails to recognise the status of a same-sex partner and as a consequence their entitlement to participate in decision-making in relation to the situation of their partner. Such discrimination may, among other things--

- affect the access of couples to residential aged care, where same-sex couples may be denied access to services
- have an impact in relation to the type of treatment that a person undergoes when they face a life-threatening or terminal illness and their 'next of kin' is involved in the decision-making process
- affect the entitlements of the surviving partner under laws relating to succession, whether the partner dies having made a will or intestate, and under other laws which permit a surviving partner to inherit property or to be eligible for a survivor's benefit.

In recent years in Australia, a range of amendments to existing laws have been made to ensure that such discrimination is not permitted, with important implications for LGBTI older persons.

C. THE POSSIBLE CONTRIBUTION OF A CONVENTION

It is of course clear beyond doubt that existing international human rights instruments apply to older persons as they do to all our members of our societies. However, existing international human rights law gives relatively little specific guidance to States and

⁶ Committee on the Rights of Persons with Disabilities, *General comment No 1 (2014), Article 12: Equal recognition before the law*, CRPD/C/GC/1 (2014).

⁷ See generally Gerard Quinn, 'The Anatomy of the Treaty Drafting Process – Lessons for the Age Treaty from the drafting of the UN Disability treaty', keynote lecture delivered at the 21st Belle R. and Joseph H. Braun Memorial Symposium and 2014 International Elder Law & Policy Conference, John Marshall School of Law, Chicago, 10 July 2014.

society on many human rights issues of particular concern to older persons. As has been noted on a number of occasions at this and preceding sessions of the Working Group, the UN human rights treaties themselves make little explicit mention of age-specific issues, although the practice under them has provided some significant elaboration of the relevance of generally formulated rights to the situation of older persons and to discrimination on the basis of age.

While of assistance, general human rights norms and their supervisory procedures have not always provided the focus that is necessary to generate targeted policies and action to address failures to ensure that all persons enjoy their human rights regardless of age.

For example, in the eleven pages of the 2010 concluding observations of the Committee on the Elimination of Discrimination against Women on Australia's combined sixth and seventh report under the CEDAW Convention, there is only one brief reference to older persons.⁸ Similarly, in the ten-page 2009 Concluding observations of the Committee on Economic, Social and Cultural Rights on Australia's fourth report under the ICESCR there is but one reference to the issue in the context of the old-age pension.⁹ And these are the two human rights treaty bodies that have shown an interest in older persons, as evidenced by their adoption of a general recommendation and general comment on the issue, respectively.

What a convention might do is to provide such guidance, by stating fundamental principles but also by specifying particular areas where States will need to take specific action. The Convention on the Rights of Persons with Disabilities provides a good example. It sets out general principles in article 3,¹⁰ many of which resonate in the

⁸ CEDAW/C/AUL/CO/7, para 38 (2010).

⁹ E/C.12/AUS/CO/4, para 20 (2009).

¹⁰ 'The principles of the present Convention shall be:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;
- (f) Accessibility;
- (g) Equality between men and women;
- (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.'

context of the human rights of older persons. But it also identifies issues of particular concern to persons with disability, such as questions of recognition of legal capacity, the vulnerability of persons with disabilities to abuse, and the right to accessibility. These give particularity to general obligations and values contained in the existing conventions. So, for example, we might find in a new convention on the human rights of older persons an obligation on States to take all appropriate measures to ensure that a person's expressed wishes about end of life treatment are given effect to, or to ensure that access to medicines for pain relief is broadly available, or that a non-discriminatory approach to different forms of family should be adopted in areas ranging from access to health care and social assistance.

While all these obligations might be said to inhere in the existing catalogues of treaty rights and obligations or to be capable of being derived from them, the fact is that only limited progress has been made in undertaking that interpretive task and applying these general guarantees to older persons' situations.

D. CONCLUSION

The reasons we have heard for not acting – or for not acting *now* – on a new convention are exactly the same ones that were repeated time and time again in the debates over the adoption of the Convention on the Rights of Persons with Disabilities, and other specific human rights treaties before that.

Some participants in the debate have suggested that we face a binary choice - between improving implementation now and the elaboration of a new convention. That is not so – both are possible, and both are desirable. Non-binding policy documents are no substitute for the force of a binding treaty.

Nor is it an adequate response to suggest that existing treaty bodies and procedures have the capacity to take up these issues in a focused and sustained manner. They are already overburdened and their processes are being streamlined (for example, with shorter reports and a move to a reporting approach based on lists of issues prior to reporting sent to States as the basis for their reports). Yes, they can improve their performance in dealing with age-related issues, but they cannot do what a new treaty would make possible. For those of us who live in a region of the world where there are no regional or similar human rights treaties – and that is half or more of the world's

population – an excess of applicable binding norms and overlapping institutions is not the major concern.

We *know* that there are significant shortfalls in ensuring the enjoyment of the human rights of older persons – ranging from stereotyped attitudes about the roles and abilities of older persons to the violation of the rights of older persons to physical and psychological integrity, and everything in between.

We *also know* that there are many areas in which violations of rights of older persons by non-State actors and failures by States to fulfil existing legal obligations are largely invisible or underreported.

We *know* that society is the worse-off in many ways as a result of failures to respect the human rights of older persons.

We *know* the situation is going to become more challenging as the world ages rapidly.

We *know* that existing instruments, supervisory bodies and international and national procedures have failed to adequately to render visible and address many of these problems and that seeking to improve these mechanisms is only going to be a partial although necessary response.

We *know* from the experience of other specialised conventions (most recently the Convention on the Rights of Persons with Disabilities) that the adoption of a focused legally binding treaty can make a significant difference – not by itself but as part of an overall strategy. It makes visible what was not seen, focuses attention on practical implementation measures, holds governments accountable to their citizens, and mobilises governmental and civil society efforts.

If we know all this, then we must conclude that there is a strong case for new convention. Our societies ask this of our governments – and we expect them to respond.

There are many important and difficult conceptual and practical issues relating to the rights of older persons, some discussed on this and other panels, that need to be discussed as part of elaborating a new instrument. It is time to get on with that job.



ASIA PACIFIC FORUM
ADVANCING HUMAN RIGHTS IN OUR REGION

Statement to the UN Open-ended Working Group on Ageing

APF Statement

Fifth Working Session of the UN Open-ended
Working Group on Ageing

30 July – 1 August 2014

Asia Pacific Forum of National Human Rights Institutions OEWG Statement

Introduction

The Asia Pacific Forum of National Human Rights Institutions (APF) is a regional network comprised of the following twenty one National Human Rights Institutions (NHRIs):

- **Afghanistan** Independent Human Rights Commission
- **Australian** Human Rights Commission
- National Human Rights Commission of **Bangladesh**
- National Human Rights Commission of **India**
- **Indonesian** National Commission on Human Rights
- **Jordan** National Centre for Human Rights
- National Human Rights Commission of **Korea**
- Human Rights Commission of **Malaysia**
- Human Rights Commission of the **Maldives**
- National Human Rights Commission of **Mongolia**
- **Myanmar** National Human Rights Commission
- National Human Rights Commission of **Nepal**
- **New Zealand** Human Rights Commission
- National Human Rights Commission of **Oman**
- **Palestinian** Independent Commission for Human Rights
- **Philippines** Commission on Human Rights
- National Human Rights Committee of **Qatar**
- Ombudsman of **Samoa**
- Human Rights Commission of **Sri Lanka**
- National Human Rights Commission of **Thailand**, and
- **Timor Leste** Office of the Provedor for Human Rights and Justice.

The APF welcomes this opportunity to contribute to the fifth session of the UN Open-ended Working Group on Ageing (OEWG).

1. NHRI Participation

The APF and its member institutions seek to positively contribute to the work of the OEWG. We therefore encourage the OEWG to provide for the full participation of NHRIs in future sessions of the OEWG based on the practices and arrangements agreed upon in General Assembly resolution 60/251 of 15 March 2006, Human Rights Council resolutions 5/1 and 5/2 of 18 June 2007 and 16/21 of 25 March 2011 and Commission on Human Rights resolution 2005/74 of 20 April 2005.

2. Asia Pacific Regional Workshop

The member institutions of the APF support the development of a comprehensive international legal instrument to promote and protect the rights of older persons.

The APF therefore brought together its member NHRIs, representatives from civil society and the United Nations to discuss a regional approach to progressing a possible 'Convention on the Rights of Older Persons'. The workshop was hosted by the Australian Human Rights Commission from 15 to 16 May 2014 in Sydney, Australia.

Discussion of substantive issues was centred on (i) a background paper and (ii) a summary of responses from a survey which was completed by APF members and stakeholders prior to the meeting. In addition to this, participants had the opportunity to discuss issues affecting older people in their own countries and what was being done to address these issues.

In line with General Assembly Resolution 67/139 which requested the OEWG to present a proposal containing: "*the main elements that should be included in an international legal instrument to promote and protect the rights and dignity of older persons...*", the workshop considered a range of issues including:

- An overview of ageing in the Asia Pacific region;
- The incorporation of the rights of older persons in existing international law;
- The progress to date for a possible convention;
- The purpose of a new convention;
- The definition of 'older persons';
- Equality and non-discrimination and older persons;
- The right to physical and mental health and care;

- Freedom from exploitation, violence and abuse;
- The right to an adequate standard of living and social security;
- The right to work;
- The right to independent living;
- General principles concerning the relationship of a possible new convention with existing international and regional standards;
- National and international supervisory and monitoring mechanisms; and
- Statistics and data collection.

A report of the proceedings of the workshop is attached. The APF submits this report for the consideration of the OEWG.

In conclusion the APF welcomes its engagement with the OEWG and APF member NHRIs look forward to actively contributing to this important UN process.