Rights of Older Persons – a Growing Challenge for the Human Rights Movement

Address to the AGE General Assembly, 13 May 2011

Ladies and Gentlemen,

It is both a pleasure and a great honour for me to be able to address you today, at the occasion of your General Assembly, on behalf of the UN High Commissioner for Human Rights, Navi Pillay, as her Regional Representative for Europe.

Please let me start on a personal note by saying that I have been involved in cooperation with AGE Platform Europe ever since I came to Brussels in 2004 – then as a member of Cabinet of the European Commissioner for Employment, Social Affairs and Equal Opportunities, Vladimír Špidla, who was very influential in placing the issue of demographic change, of population ageing, on the European Union’s agenda.

Over the years that followed, I have had many opportunities for close and constructive cooperation with AGE – and in particular with your Director, Anne-Sophie Parent – on several issues. But there were three major themes on which we cooperated that stand out in particular, and I believe they deserve to be mentioned here, because they are undoubtedly of continued relevance to senior citizens’ organizations, and they are of great importance also to the OHCHR’s Regional Office for Europe because they constitute genuine human rights challenges.

Older persons in institutional care

The first among these three issues is that of rights of older people in institutional care. Here I would like to pay tribute to an extraordinary man, who was an American but whose achievements should be equally inspiring to us here in Europe – Robert Butler.

Almost 40 years ago, in the 1970s, in his groundbreaking book *Why survive? Growing Old in America*, Robert Butler drew attention to the problem of old people surviving miserably in care homes. He showed – as did other researchers and activists after him – that even in the richest and most developed countries in the world, many elderly people spend the last phase of their life in situations that are simply degrading. And in an echo of the 1960s movements for the rights of women, of racial, ethnic and sexual minorities, these researchers and activists (among them increasingly the older persons themselves) called for change.

I had the opportunity of meeting Robert Butler in Sankt Gallen not so long before he passed away last year, at the age of 82 – and it was clear to me that he himself had found out why it makes sense to survive into old age: remaining highly active, productive, contributing to society as a professional and as a participant of an inter-generational discussion. (And there are many outstanding examples of older people making great contributions at even higher age – the last living drafter of the Universal Declaration of Human Rights, Stéphane Hessel, with his new influential book addressed to young people, at 93; film director Manoel de Oliveira, who is still filming one excellent film a year at 102; architect Oscar Niemeyer, still active at 103, etc.) But many problems that Robert Butler had described have remained with us, and with population ageing they are perhaps even more important than before.

In the last four decades, the baby boomers moved from being the young generation to being the pioneers of active ageing at an unprecedented scale. The perception of the role of older people has changed significantly in many societies – significantly, but not sufficiently.

We still have many care institutions around Europe where the elderly users are provided care in ways which follow the organizational needs of the service providers rather than the
individual needs of the users; in ways that compromise their dignity and afford little or no autonomy and privacy. Impersonal and instrumental treatment diminishes them as human beings and leads to emotional suffering.

But often there is even physical suffering. There is growing evidence that older people in care, including health-care facilities, often deteriorate in their health status due to dehydration (which can cause them to be wrongly labeled as suffering from dementia, and which can lead to death). Elderly people with real cognitive disorders – as well as those whose cognitive status has deteriorated due to neglect by staff – are still often facing inhuman treatment such as restraints or routine administration of medication such as tranquilizers or neuroleptics, “so as to make work easier for the staff”, which further aggravates their condition.

Similar indignities are not infrequently encountered by other groups of persons in institutional care – persons with physical and intellectual disabilities or mental health problems as well as children who have been abandoned or removed from their families by social services. Moreover, some of these categories are increasingly overlapping: Unprecedented numbers of persons with lifelong disabilities now reach old age, while growing numbers of elderly persons can now be seen as having a disability, and benefiting from the protection offered by the recently adopted International Convention on the Rights of Persons with Disabilities.

I am convinced, therefore, that there is a need to address these challenges jointly. And I would like to salute AGE’s decision to join, since 2009, the expert group on the Transition from Institutional to Community-based Care, created by the European Commission and involving organizations focused on advocacy (for right of persons with disabilities, mental health problems or children) as well as the European Association of Service Providers for Persons with Disabilities. I believe the report of this expert group, and its subsequent work, is a real source of inspiration on a European level.

How can these challenges be met?

On the one hand, there is a clear need for standards of quality to be developed, adopted, implemented and monitored. And I would like to stress that these standards should not refer mainly or exclusively to material conditions, but also – and above all – to the empowerment of the users, including older persons, as active subjects, and not mere objects of care.

On the other hand there must be increased attention to the right of older people to decide for themselves where and how they wish to live, with an emphasis on the development of community-based services to enable or facilitate a choice of continuing to live independently or within a family environment with adequate professional support. After all, when Article 19 of the UN Convention on the Rights of Persons with Disabilities, which lays down the right to independent living for persons with disabilities, it obviously does not mean that this should be a specific right for them; it stresses that even persons with a disability should have that right, which is otherwise taken for granted.

Of course, where institutional care is the only alternative to abject poverty, neglect and isolation (as we have seen in remote areas of Eastern Europe where abandoned elderly people are at risk of literally dying of starvation), even low-quality institutional care is often perceived as progress, just as it was in many other parts of Europe in the late 19th or early 20th century. But in the 21st century, in such an advanced part of the world as the European Union, the availability of real choice should become imperative.

The OHCHR Regional Office for Europe is planning, in cooperation with the International Institute on Ageing, a colloquium on the use of human rights violations concerning older persons – such as the use of physical restraints and pharmacological sedation and restrictions of freedom in the context of long-term care – which is tentatively scheduled for
January 2012 in Malta. We would, of course, very much welcome the cooperation of AGE Platform Europe in preparing this event.

Elder Abuse

Another theme that which requires to be seen as a human rights challenge is that of elder abuse and neglect. As clear from the abusive practices that I have mentioned earlier, it overlaps significantly with the intrinsic problems of institutional care, but it also concerns older people living at home, mostly in a family environment.

Indeed, although we have only very incomplete data, it seems that the majority of cases of full-fledged elder abuse occur within the framework of informal rather than formal care, if only because the vast majority of elderly people do live in their own homes rather than in care institutions. And while most family environments are warmer and far more emotionally satisfying than impersonal conditions of institutional care, in a non-negligible minority of households there is also a real risk of things going very wrong for a long time without outside intervention – due to deliberate exploitation or harm inflicted upon the older person by a relative, due to inter-personal conflict, or else due to burn-out of the informal carer who receives little or no support from society and ends up doing wrong despite his or her initial best intentions.

Is this just a family matter, or a human rights issue? Who are, in human rights language, the “duty bearers” in such situations?

I am convinced that it is a human rights issue that should be addressed by the States – through measures focusing on prevention, through support to informal carers, respite care, awareness raising and in many other ways. The issue should also become far more prominent in the activities of the broader human rights movement and of international human rights mechanisms, where it has so far been almost invisible.

The first European Conference on Elder Abuse, organized by the European Commission in close collaboration with AGE in 2008, can serve as yet another source of inspiration. Unfortunately, most of the follow-up actions (as proposed to the EU institutions and Member States in the closure of that conference by Anne-Sophie Parent) have been carried out to a very limited extent, if at all. Perhaps it is time for the Office of the High Commissioner for Human Rights, together with AGE, to place this issue once again on the Brussels agenda in the year to come?

Age discrimination

Finally, the third human rights issue on which I have had the opportunity to work closely with AGE Platform Europe in the past is that of legal protection from age-related discrimination. Again, this is an area where progress has been achieved in Europe, but major obstacles remain. Above all, the ambitious “horizontal” directive, the one that would protect persons from discrimination on the grounds of age (as well as disability, religion and sexual orientation) across a whole range of areas from social protection to access to goods and services, was proposed by the European Commission in 2008… but has since then remained heavily contested in the Council, where it requires unanimity, and where it faces stiff opposition from some Member States.

In this context, I would like to acknowledge the support of this draft directive by AGE Platform Europe, which has maintained active solidarity with other groups representing other discrimination grounds. It seems to me that we, the human rights community, should also not resign on this proposal – indeed, the High Commissioner has been constantly reminding EU Commissioners as well as political leaders of EU Member States about it – and, moreover,
that we could try to increase the general public's awareness of some of the concrete
discrimination problems that are frequently encountered by the groups involved, including
older persons.

One such concrete issue is that of discrimination of older persons in access to health care.

In many parts of Europe, we are witnessing a not-so-new but newly resurgent phenomenon
of denial of adequate health care to older persons. The justification is mostly economic and
the current economic crisis serves as a powerful driving force. The logic goes as follows – if
older patients do not present (as younger people do) with a single diagnosis that could be
cured, but rather with multimorbidity and frailness, then it is alleged that medicine is not the
right answer for them at all; that they need to be labeled as "social cases" and placed in such
care institutions providing little if any health care.

But the choice between the same medical approach as to everyone else and no medical
approach at all is a false one – it is wrong ethically, because it stems from discrimination, but
it is wrong even in terms of practical, "objective" outcomes. In fact, older people are often
receiving far too much medication (which itself is, indeed, one of the principal causes of
health problems in old age). We all agree that older people should not become prey to
relentless advertising by pharmaceutical companies that would like to see them consuming
more and more drugs, including those that had only been tested on younger adults, with
unforeseeable consequences. And indeed, older people in long-term institutions should not
be permanently bothered by rigid hospital-type routines nor forced to wear hospital clothes all
day. But that does not mean that the only alternative to "medicine as usual" should be
therapeutic nihilism!

On the contrary, there is a third option, which is the right one. The fact that multimorbidity in
many older persons cannot be dealt with in the same way as single-diagnosis issues in
younger people should be a strong argument for their access to holistic geriatric medicine,
including acute geriatric care, which can often resolve or improve problems ignored or
created by uncoordinated actions of specialists, as well as those caused by simple neglect.

Conclusion

Ladies and Gentlemen,

As far as human rights of older people are concerned, we are now living in eventful times.
Last month, the Open-Ended Working Group on the Rights of Older People, composed of
representatives of UN Member States, met for the first time in New York to mark the
beginning of a process aiming to identify how human rights of older people can be
strengthened in practice.

The creation of a new UN Convention specifically for the rights of older people is one of the
possibilities, though I hasten to say that there is no unanimity in that regard. A new
Convention would certainly have the benefit of highlighting the importance of rights of older
people and helping to prevent them from being forgotten again and again.

Also, it could be argued that age is one of the important discrimination grounds finding its
way into national legislation (and one of the 6 discrimination grounds contained in EU
Directives). On the other hand, age as a category in non-discrimination law applies also – and
in Employment Equality Directive 2000/78 even predominantly – to people who are not
over 65, but rather to the category of the middle-aged, between 40 and 65; so the
relationship between "age" as a ground for non-discrimination and the rationale for a specific
instrument dealing with rights of older people is tangential rather than direct.
Anyway, on that issue – whether there should be a new UN Convention on the rights of older persons – the jury is still out, and it is not likely even to be dominant during the early stages of the deliberation of the Open-Ended Working Group. Meanwhile, a number of real-life challenges for human rights of older people are looming; and we need to mobilize all the possible synergies between senior citizens’ organizations, broader civil society (on an inter-generational basis) and international human rights instruments and experts to tackle these challenges.

Let us embark on that journey together!

Thank you for your attention.