

CONFERENCE PROCEEDINGS

European Conference on Care and Protection of Senior Citizens

“ The Dignity and Hazard of Elderly ”



Under the patronage of EU Commissioner **Vladimír Špidla**
and **Michael Kocáb**, minister of human rights and minorities of Czech Republic

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A. OPENING AND INTRODUCTION SPEECHES



Michael Kocáb, Ministry for Human Rights and Minorities of the
Czech Republic

Dear Eurocommissioner,
Dear Madam President,
Dear Chairman,
Ladies and gentlemen,

It is my great pleasure to welcome you to Prague for the European Conference on the Care and Protection of Senior Citizens. The subheading for our meeting reads "The Dignity of, and Threats to the Elderly" If this conference is to discuss threats to the elderly, then we should acknowledge that they are most under threat from lingering stereotypes in the public's thinking. The media and experts sometimes, and here I must emphasise, injudiciously and in my opinion dangerously, rank the ageing of society as one of the negative trends of our time. Many of the fears of the elderly are reinforced by such statements.

Society considers old age as moving down a slope and links it to the loss of human powers, as a dispensable stage because of its unproductive nature, and as a burden to the younger generation.

Older people then succumb to these images and become that which society in its prejudices sees them as. Then people turn in on themselves and become lonely, they lack assertiveness, are frustrated, bitter and unfriendly in their own self-defence. The gap - the abyss - between the generations grows, in spite of the fact that each of us has either crossed this abyss or will cross it one day, without even knowing how. Because human life is a continuum. Human life cannot be sliced up like a loaf.

It will take much patient effort to change these prejudices. Particularly in the heads of specialists, academics, doctors and carers. Because in these fields also a high degree of sophistication on the component processes has become established. And the holistic nature of human life is neglected.

That barriers to a fulfilled life in old age arise from this view is perhaps obvious. And not only barriers in attitudes and behaviour towards the elderly, but conscious and unconscious barriers in state legislation.

This is a task which I consider my own, one which arises from my duties. To promote respect for all of human life, and to arrange for its protection through legislation.

And also to influence and (I have no fear in saying this) educate society - that is, everyone, into seeing ourselves in everyone. And that means in the old, the frail, and the dying.

This is a fundamental ethical principle. If it were part of our consciousness, we would not need laws forbidding, determining and always in their own way limiting human life.

The extension of the human lifespan is one the greatest successes of the modern era. A longer lifespan is the hope, the challenge which medical science puts before us. But all of us, including the doctors themselves, decide on whether this opportunity will be fulfilled. Because the mere prolonging of the number of calendar days on this earth cannot be enough. We must work and strive for what these days are to be like.

And when we speak of the dignity of old age, we must see behind this phrase not only people who are capable of an autonomous, independent life, but often people who are frail, often forgotten by their own family and friends, excluded from employment, public life and the chance

to learn, to obtain information in an appropriate way and, as they see fit, to obtain a variety of services, from financial, to social and health needs. The actual ageing of society is not a threat. But we should heed the warning of the social exclusion of an ever greater number of people when compared to the improving conditions for life, health care and an increasing human lifespan.

The conditions of life in old age are affected by changes in society, including changes taking place in households and in the structure of families. I trust that the Prague conference will deal in depth with these changes and will propose measures which are also essential for the care of senior citizens and for their protection.

The question of the ageing of society is not only a challenge in calculating the optimum pension system and the funding of health services for senior citizens. For all of us gathered here, it is a matter of the indispensable strengthening of the human rights aspect and of equal access to services in health, education, social services, transport and housing, all adapted to the needs of disadvantaged senior citizens.

It is not easy for me as a member of the government of the host country to say that it is precisely senior citizens who, according to research, are considered the group in Czech society which is most subject to discrimination. Judge for yourselves:

From Eurobarometer research, published by the European Commission in January 2007, it can be seen that almost half of the EU population is convinced that age discrimination is widespread in member states. At the level of the Union as a whole the issue of age is regarded as the fourth most widespread of six discrimination characteristics. Moreover in recent years there has been a rapid increase in Europeans' conviction that the elderly are discriminated against.

In the Czech Republic the situation is even worse: age discrimination here is, according to the research mentioned, the most widespread and most rapidly deteriorating problem among all determined causes of discrimination: gender, disability, sexual orientation, ethnic origin and religion. In a comparison of the number of people who regard age discrimination as widespread and worsening, the Czech Republic is in a worrying second place among the twenty-seven European countries.

The situation on legislative protection and also on people's awareness of the rights of the elderly is alarming. The Czech Republic is the only one



Minister Michael Kocáb during his speech

of the member states of the European Union which has not yet adopted an anti-discrimination law.

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On the other hand, the Czech Republic has a coherent National Programme of Preparation for Ageing for the period 2008 to 2012. In its policy on ageing the government has taken the following priorities into account:

1. Support for the family and an improvement in social services
2. Creation of an environment and a community which are friendly towards the elderly
3. Improvements in senior citizen health and health services for senior citizens

Support for the involvement of, and protection of the dignity and rights of, senior citizens

The National Programme of Preparation for Ageing is based on international materials, including the UN Principles for Older Persons and the Madrid International Plan of Action on Ageing and other documents. The application of this programme is monitored by the Government Council for Senior Citizens and Ageing of the Population. This Council is composed of Deputy Ministers, employers' representatives, employees, specialists, NGOs and of course of senior citizens themselves, who in this way play an important part in dealing with topics linked to ageing. As an EU member state we recognise that the issue of ageing must have a key place in the formulation of state policy. Let us then consider whether an analogous institution should not also be set up at the level of the European Commission. At the very least so information can be gathered and solutions proposed.

The European Union leads the world in promoting standards of equality and rights for all. The aim of the EU in the process of the social and economic integration of the elderly should be the creation of a comprehensive, coordinated and active approach to securing a good life for people in the context of a society which is ageing. For this reason it is appropriate to consider a debate on a convention of rights, responsibilities and the involvement of the elderly.

The EU has the vitality and ability to resolve not only the problems of discrimination, but also the causes of contemporary unemployment,

poor living conditions and the subsidiary costs of reforms. For this it can also make use of significant financial resources, particularly from the European Social Fund as the principal EU financial instrument for social integration.

But money does not of itself provide solutions. The European community therefore guarantees the elderly a high level of legal protection. European law ensures equal treatment for people in the labour market and in access to specialist training regardless of age. At the present time a discussion is taking place on a new Community Directive aimed at protecting people from discrimination in areas other than the labour market. It should prevent discrimination especially in:

- Social security, including social insurance and health care
- Social benefits
- Education
- Access to goods and services including housing

The economic and cultural maturity of the countries of the European Union form the basis for the development of systematic Long Term Care, available to all. It is characterised by coordinated linkage of services and measures and the breaking-down of barriers between different departments, institutions and jurisdictions. I consider it essential to support such a concept of long-term care, which emphasises the meaningful existence of every human being. Its basis must be the right to life in a familiar and natural environment. To respect the right to choose a place to live and to die, a home for life. To respect gender diversity and strengthen the protection of older women. To respect also the religious and cultural diversity of the frail and elderly.

By the method of active prevention, to prevent all forms of unsuitable treatment on the part of carers (family members or professionals), neglect, abuse or even cruelty (domestic violence, unjustified restraint) to elderly people. EU countries have varying degrees of experience in securing respect for and the rights of people threatened with neglect or the abuse of their rights. I consider it important to strengthen cooperation and exchange of good practice in dealing with this serious issue in EU countries and to make it one of the topics for cooperation.

Dignity, self-respect and security must not be in doubt for even the most frail and vulnerable senior citizens - for those close to death or suffering from the advanced stages of dementia. They must not become merely the material objects of a kind of low-cost care taken of

their most basic biological needs. These people too should be allowed a worthwhile life within the options offered by modern science. Nor should the growing numbers of very old people lead us to considering the legalisation of active euthanasia by medical staff.

Europe's wealth has always been in the potential of its people. The quality of our civilisation has come from supporting and developing opportunity for all; and at all stages of life. This is a value which we must not lose!

Ladies and gentlemen,

This Prague conference follows on from previous conferences of European presidencies, the recommendations and material of European political and specialist gerontological discussions.

In the Declaration which I hope this conference will issue, the challenges to the European community and to all citizens of the European Union are formulated in very clear language.

Old age is not be perceived as a dangerous phenomenon, but as a challenge. Old age is a new source, albeit qualitatively different, of further growth for society. The public activities of the elderly are to be supported in the same way as improved public awareness of ageing and the lives of the elderly. Respect for old age must be increased. We must prevent inappropriate treatment of old people, including neglect, abuse and even violence.

At the level of European institutions a joint concept of long-term care should be developed. It is necessary to consider whether the EU can guarantee unified standards of health care provision for senior citizens in all member states, and if so, how. Within the Union's operating and consultative bodies, but also between countries and regions, there must be efficient exchange of information and practical experience. For this we need to improve our use of the latest technology. As an example the Czech Presidency has come up with the concept of "E-health", which should be supported.

At a time of economic downturn and a reduction in incomes we must ensure adequate funding of the health care and services which are a prerequisite of a dignified life in old age. Within the EU we promote freedom of decision-making for individuals and thereby the principle that services should come to the individual and not the individual to the institution.

The Czech Presidency also emphasises improving the active lives of senior citizens. All activities for the elderly, including those of an educational nature, should also be funded from EU structural funds. Inter alia, these services and activities will also have an impact on improved employment. In those parts of Europe where it is difficult to obtain any kind of work, it is these services for senior citizens which could be a welcome opportunity for maintaining quality of life into the future.

Support should also be provided for scientific research into all aspects of life in old age and into ageing, so that the scope and quality of research projects corresponds to the importance of the changes in contemporary society. We call for support for the development of training in gerontology and geriatrics. Europe must not neglect measures, especially media measures, directed at correcting society's view of the role of older generations and of life in old age.

Ladies and gentlemen,

I am convinced that the conclusions of our discussions will be listened to with great seriousness by the representatives of European countries and the institutions of the Community. And I believe that they will be adopted and implemented in the legislation of the Community, its countries and in the life of society as a whole. For this reason also allow me in conclusion to wish this conference every success as it deals with questions which affect us all.

I thank you for your attention

Jan Lorman, Chair of the Conference Steering Committee; Chair of the ZIVOT 90 Civic Organization

Dear Eurocommissioner,
Dear Minister,
Dear Madam President,
Dear Mr Zeleněv,
Dear Deputy Minister,
Professor,
Ladies and gentlemen,

Welcome to the European Conference on the Care and Protection of Senior Citizens - Dignity and Threats in Old Age

We have invited you to this conference and you have accepted our invitation. This is excellent. I make so bold as to hope that you have come to help us meet the aims of this conference. For this I thank you.

I welcome also viewers of internet television, which will transmit the proceedings of our conference throughout the world. I am very pleased to welcome the spectators of Internet TV! Hello! Good morning! Good afternoon! Good evening! At the moment it may well be good night where you are!

Why did we initiate the organising of this conference?

We started as early as 2007 because we were involved in the preparations for the European Conference on Protecting the Dignity of Older Persons, which took place in March 2008. We wished to build upon that conference.

We considered it beneficial for the Czech Presidency of the EU Council to support the topic of dignity for senior citizens, particularly in the context of the reform of health and social services and in the context of so-called long-term care.

And as particularly beneficial its understanding in the context of the centre theme of "Europe without Barriers". As part of this and in the context of an ageing population we consider as fundamental for the Czech Republic and other EU countries the increasingly discussed question of "age barriers" (age discrimination), in connection with both health care and the market for goods and services and with social inclusiveness (active ageing).

"Europe without Age Barriers" or "An Age-Friendly Europe" is a topic which makes the general topic of "Europe without Barriers" more specific, has in it an ethical charge, a strong message and serious economic consequences, includes the question of human rights and social inclusion, the general topic of adapting policies, public services and so on to the growing number and proportion of older and very old people in the countries of the EU, to phenomenon of population ageing and the onset of the long-lived society.

What was at the root of the need to organise the conference?

The topic of bad treatment of senior citizens, or elder abuse, is a very broad issue, urgently requiring international clarification. It is clear that if attention is to be directed generally at "abuse", it will cover too many

problems which are difficult to grasp. For this reason it is essential to choose specific problems and focus on individual types of abuse and the legal and other instruments to deal with them, i.e. on the protection of senior citizens and the elderly who need long-term health and social care from financial, housing and property abuse, loss of liberty, and from poor and inadequate care.

As the most important we consider preventative activities, the prevention of social isolation of vulnerable old people and the whole family as well as their carers, the availability of a confidential relationship, e.g. with a doctor.

It is our judgment that detailed measures must be based on the fundamental concept and wider context of social ageing and that by contrast this concept must grow out of documented detailed facts. The most well-meaning proclamations or the most frequent formal agenda discussions will not help us. We must rigorously base our work on specific phenomena, on the situation of specific people and strive for specific solutions, to meet a series of detailed objectives.

Without doubt very much must be achieved on the issue of the elderly under severe time pressure.

We are aware of the scope and danger of negative social myths on old age, of demographic alarmism, of the phenomenon of abuse and political manipulation of old people. It is above all from these systemic roots, from ignorance and poverty that most symptoms of elder discrimination, humiliation, abuse, neglect, inappropriate treatment and avoidable suffering arise. The brutality of physical violence, systematic cruelty and other extreme symptoms often linked to personality traits of the perpetrators are, in spite of their vileness, only an adjunct to this social mega-problem. If we were not to resolve it, then films like "2030 - Revolt of the Elderly" will no longer be mere science fiction.

In the area of information and education we feel an urgent need to analyse the role of the media, which not only modulate the social mood, but very often directly invent reality. If they are unfriendly towards senior citizens, this is a significant element of ageism and abuse.

A similarly linked symptom is the passivity of some old people, who comfortably refuse to take responsibility for their own lives, including education. If we cannot win them over to active personal development,

Mr. Lorman during his speech



their disadvantage and vulnerability will be all the more marked. Effective education of civic society should in the spirit of subsidiarity emphasise the role of volunteers and communities in striving for meaning, dignity, integrity and security of life in old age, including solving elder abuse.

The objective of the conference is a positive shift towards a unified view of this issue both within the European Union and in the interna-

tional community in general and also in interdisciplinary dialogue, which must offer a political realization backed with an indication of the direction. Finding solutions should be an essential contribution to the Prague conference.

We sense serious lack of clarity around the very nature of geriatric frailty, disability in advanced old age, the ethnical aspects of medical and social intervention including the use and abuse of restraint methods and information and communication technologies, the modified nature and management of health care exceeding the so-called disease model, the dominant focus on diseases and not on the patient's status.

We find that many frail geriatric patients suffer without dignity, are manipulated and neglected in the "no man's land" between specialised medical fields and on the social health edge, if geriatric medicine is not adequately developed. We also feel the need to clarify and unify the terminology, in order to smooth the path for electronic monitoring, European information sharing, comparison, standards equalisation and continual care during the growing movement of clients and personnel.

The significance of these detailed problems is determined by the fact the issue of so-called long-term care was socio-politically conceptualised only recently (e.g. as part of the transatlantic conference of the European Union and the USA here in Brussels in September 2006).

This Prague conference can be understood as a search for a European path to the implementation of frail old age and the concept of long-term care in strategic political management.

Good fortune shone on the intention to organise a European conference on this topic. It was supported by the Czech Government Council for the Elderly and Ageing Issues, by the then Minister for Human Rights Mrs Džamila Stehlíková and her successor Michael Kocáb, as well as by Deputy Prime Minister Alexander Vondra. And thanks to Eurocommissioner Vladimír Špidla it was also favourably received at the European Commission.

Vladimír Špidla, Commissioner for Employment, Social Affairs and Equal Opportunities

Ladies and gentlemen,

I am very pleased that I can be here with you today, because the topic of the rights and the dignity of senior citizens is one I consider urgent from political, ethical and human point of view.

In this regard I would like to thank the Czech government for organising this conference, and in particular Minister Michael Kocáb and his team, as well as the representatives of civil society, above all its promoters, Mr Zdenek Kalvach and Mr Jan Lorman of the Život 90 organisation.

Demographic trends and their consequences

A few years ago in 2005, the so-called European Commission Green Book initiated a pan-European discussion on demographic changes. Thanks to this debate it has been possible at least to a certain extent to draw attention to topics which had up to that time often been overlooked. One of these is this very question of the position of senior citizens in society and the guarantees for their rights and human dignity.

And still today - particularly in the conditions of an economic crisis - the topic of the position of senior citizens in society is hard to promote in "competition" with other topics, which have at first glance a clearer economic significance. I say at first glance because I am convinced that the ageing of the population is, even from a purely economic perspective, a more significant and long-lasting phenomenon than the present crisis.

The way in which developed societies of the 21st century deal with this phenomenon will in my opinion be the key to their further success - and not only in a purely economic sense.

As life spans increased in European societies not only does the absolute number of older citizens increase, so also does the proportion of the population they represent. But what is and will be the QUALITY OF LIFE of these people? What does it depend on?

Part of the answer will without doubt concern health: not only these individuals themselves, but public policy also, should strive to have these people attain greater ages in good health. This of course means not only health care as such, but also a healthy lifestyle, with health protection in the workplace throughout one's working life, and a healthy environment.

The quality of life in old age cannot however be reduced simply to the health dimension. It also has its social dimension. Here I do not have in mind only that which politicians often imagine when they hear the word "social", that is, the value of pensions and other material conditions. This is all without doubt significant; but a part of the quality of life of senior citizens is also its social dimension in the wider sense of the word, encompassing the economic and social activities of senior citizens themselves, from their earning capacity to their volunteer work.

Current trends indicate that the large post-war age-groups will not only live to a greater average age, but will on average be healthier and more active than the preceding generations of senior citizens. Today these strong age-groups are beginning to fill the ranks of so-called younger senior citizens over the age of 65. Demographic forecasts of course also point to the fact that the fastest growing age group in European populations in the coming decades will be those over 80 years old. And to this will be linked - even with an assumption of improved health and greater senior citizen activity levels - very probably to greater demand for long-term care.

Long-term care and its quality.

As is also shown by recent analyses prepared by the European Commission, this trend will require not only increased financial resources, but especially investment in the people who care for senior citizens.

This is not just an economic calculation - on the numbers of beds needed, or even just the number of workers needed - but is most of all about what the QUALITY OF CARE PROVIDED is and will be.

Care for senior citizens is in fact often mentally and physically demanding, both for professionals and for family carers.

In the current conditions both of these groups often encounter great difficulties. The work of sisters, nurses, rehabilitation staff, social workers and other caring professions has not to date been suitably valued - both in terms of pay and social standing. Very often it is not easy for these staff to gain access to ongoing or lifetime education. In these situations there is the risk that their work with senior citizens becomes merely mechanical routine, or even that burn-out syndrome will occur.

Often however the situation of family carers is also difficult. In families the care of the elderly is performed mainly by:

Women who must often combine this work with caring for other family members ("the sandwich generation") or with work as well;

Family members who have lower levels of educational achievement or have lost their jobs and are unemployed.

To a growing extent family care is undertaken by persons other members of the family. These are people for whom it is their personal choice: friends and volunteers

But of course family carers need not only suitable material conditions, but also the possibility of time off and often a certain level of specialist training.

For all of these reasons I consider it important that member state governments and EU institutions arrange for specialist support and targeted training - both for professional carers and for family members caring for senior citizens and for other informal or semi-formal carers, for example for volunteers.

High-quality care for senior citizens should be individualised to the greatest extent possible, to respect the differing needs of every individual. In this regard we are increasingly aware that of great significance for the quality of life and dignity of senior citizens - just as for other groups - is the maintenance of the greatest possible level of autonomy and decision-making in one's own life. To the greatest extent possible, every person should be should be an active subject, and not merely an object of care.

Senior citizens should therefore have the option to use such services as will allow them to remain in their own homes, should they so wish. For this reason support for community services, which creates a certain

alternative to those models in which institutional care has dominated so far, is seen to be desirable

Poor treatment and threats to the human dignity of senior citizens

When we speak of the quality of care, we cannot avoid the issue of poor treatment of senior citizens and threats to their human dignity (ELDER ABUSE).

Sometimes the cause of this phenomenon is a lack of respect and sensitivity towards senior citizens or prejudices against them, known in the international literature as AGEISM.

In some countries a part is played in poor treatment of senior citizens by the continuation of a general paternalistic culture of care institutions and families. This is a kind of obvious assumption that every recipient of care should be grateful that he or she receives any care at all, and should not put forward views of their own.

But often poor treatment is not based on malicious intent, nor on prejudice or paternalism, but simply on inadequate knowledge or lack of preparation for stressful working conditions.

It is for this very reason that not only support for improved qualifications for professional carers, but also support for family carers, are so important.

Permit me at this point to put forward two views of my own:

1. I am convinced that a useful part of the improvement in qualifications for carers could be the exchange of experience between workers from different EU member states. In recent decades a number of members have already achieved marked changes for the better in the quality and institutional culture of services for senior citizens. Others are only at the beginning in this process. I consider it wise to overcome inertia and to take inspiration from the example of other countries - and sometimes to learn from their mistakes.

2. I am of the view that part of general education - that is, the education of all citizens, not only those working in the caring professions - should be preparation for life with senior citizens. After all, preparation for parenthood is now part of general education in most countries.

European Union activities

It is clear that the main powers in the area of services for senior citizens remains at the level of member states themselves, their regions and communities. The European Commission together with other EU institutions is nevertheless developing a number of activities which deal with this topic in one way or another. Some countries have designated the topic of senior citizens has a priority for their presidency of the EU Council and have organised conference on this (Luxembourg in 2005, Slovenia in 2008, they will be joined in a few months' time by Sweden.)

In addition there was a conference in March last year in Brussels, where for the first time at EU level we discussed prevention of poor treatment of senior citizens and their neglect. Today we are building on the results of that conference.

As part of the so-called "Open Method of Coordination" in social matters several seminars have taken place (e.g. in the Netherlands and in France) with the aim of comparing systems and practice. Further such seminars are in preparation.

Mr. V.Špidla during his speech



The European Parliament expressed concern over the problem of poor treatment of senior citizens in its Resolution dated 21st February 2008, on the demographic future of Europe. In it, it requested that the Commission arrange a pilot for prevention of poor treatment of senior citizens. Thanks to this a call for the presentation of project proposals is currently in preparation. It will provide financing for the following kinds of projects:

Monitoring of poor treatment of, and violence against, senior citizens

Mapping of existing policies and approaches with the aim of identifying suitable models.

At my initiative an expert group on the reform of institutional care was formed at the beginning of this year. We wish to support member states in further moving from institutional care to individualised forms of community care - not only for senior citizens, but also for children, the handicapped and those suffering from mental illness.

Ladies and gentlemen,

The history of human rights is also the story of increasing sensitivity of society as a whole to the rights of "others" - first women, then members of ethnic minorities, the handicapped, children, senior citizens.

This story has not by any means reached its end. It is up to us all - to representatives of public authority as well as the representatives of social partners and civil society in the widest sense - to continue this humanist narrative. We still have much to do.

I believe that this conference will contribute to increasing the sensitivity of society as a whole to the topics of care for senior citizens, their human rights and dignity.

I thank you for your attention.

Dear Colleagues, Ladies and Gentlemen,

It gives me particular pleasure to address European Conference on care and protection of senior citizens. It is an honor to be invited here and I sincerely thank the organizers of the Conference for this opportunity.

The issue of dignity of older persons and protecting their rights is one of the major concerns of the UN at the intergovernmental level. In this light I wholeheartedly commend the organizing committee for coming up with this idea of the Conference that has so many practical implications and is important for many people in Europe and around the world.

The world is ageing and the number of older persons worldwide continues to grow. Although older persons enjoy civil rights in most countries they may be unable to defend them in situations of abuse and neglect. Elder abuse is a multifaceted phenomenon which has a long history. Early detection and prevention of elder abuse is vital for the protection of their dignity. The Madrid International Plan of Action specifically indicated that elimination of all forms of neglect, abuse and violence of older persons remains a primary objective of public policies; the Plan also sets a number of support policies to address the problem.

Enacting legislation that strengthens legal efforts geared at prevention and elimination of elder abuse is a vital first step but it is only a first step. Much remains to be done at the micro level, at the level of communities but also families.

In 2007-2008 the UN Commission for Social Development undertook review and appraisal of the implementation of the Madrid Plan. This exercise revealed that in many countries, older persons continue to be excluded from full participation in political, social, economic and cultural areas of societal life. The barriers that preclude their inclusion are well known. It is poverty, poor health, low educational levels and lack of transportation and access to services. But apart from that, existence of negative stereotypes about ageing and overt or subtle age discrimination should not also be overlooked as it creates a fertile ground for abuse and neglect.

Abuse of the elderly is first and foremost a betrayal of trust and as such it has very high cost for older persons in moral and emotional terms, and

often has health implications. As research demonstrates, abuse can occur anywhere-- in the family, in the hospital, or nursing home. It is also well known that both older men and women are vulnerable to abuse. Most often the abuser is someone whom the abused knows very well and may even trust. Many forms of elder abuse are akin to domestic violence or family violence and should be treated that way.

The real issue, when we discuss the prevalence of abuse against the elderly is the need to shed light on the darkest corners where this situation can occur, and not to be afraid to speak publicly about negative phenomena which exist. Invisibility of abuse is still widespread and remains a real challenge. Mistreatment of older persons flourishes when it is ignored at the policy level or by public at large. The first step is to acknowledge that such problem does exist and policy solutions must be found.

Common definitions of abuse are sometimes lacking and this creates substantial problems when addressing the complaints. Of course, it is a very emotionally charged issue and it is sometime difficult to discuss this issue but it must be discussed and society must be fully aware of the scope of this occurrence as well as ways and means to address the situation.

In this light I would like to stress the need for sound and forward-looking family policy. Around the world many older persons continue to live in families. Family is one of the ancient institutions but it is also an evolving institution. The need for family-friendly policies and programmes is widely acknowledged. Whether we are talking about financial support through tax and financial benefits, or about a family approach to health care, or quality programmes to promote parental competencies, it must be complemented by a set of policies specifically aimed at preventing the abuse neglect and violence against older persons. And it should start with awareness raising and some elementary training of family caregivers or family members at large. Intergenerational solidarity is a particular significant dimension in this respect: erosion of bonds between generations has detrimental effect on older persons.

While awareness raising on issues of ageing and elder abuse is essential, it should be done in cooperation with all stakeholders. Given that older women face greater risk of physical and psychological abuse due to existence of discriminatory societal attitudes, their situation requires particular attention. Of course, society cannot overlook the existence of

some very harmful traditional and customary practices that may result in abuse and violence directed at older women. Witchcraft accusations and other harmful practices may be an extreme case but they are still prevalent in several African countries, often leading to violence against older women. Rampant poverty and a lack of access to legal protection often exacerbate the situation.

A range of measures to address neglect and abuse of older persons is well known. It involves education of the general public using media and other means which increase awareness in society. It definitely involves creating conditions for sensitizing health care professionals who work in nursing homes and other medical establishments dealing with the elderly.

When we are talking about effectiveness of policy measures we should not overlook the need of a much better nexus between research and policy action. We do need better research on the issue of mistreatment, we need more insights about the causes of elder abuse and neglect, about the contexts in which these infringements occur as well as consequences of elder abuse for older persons. This nexus between research and policy is reinforced through cooperation of the Government bodies with research institutions dealing with various aspects of gerontology and geriatrics. But, it also involves important steps undertaken by the Government officials within Ministries who approach this issue in a comprehensive and holistic way, seeing a full spectrum of problems. Depending on a country's circumstances, it may be quite important to establish a focal point within Ministries dealing specifically with issues of abuse and neglect of senior citizens.

There are various instruments that could be used. In many countries the hotlines have been established that accept calls regarding the suspected abuse. Cooperation with law enforcement agencies is vital here. Given the evolving demographic situation and increase in the cohorts of older persons, it is very obvious that the creation of such focal points within government structures could be very timely. If done properly and efficiently, it could bring tangible benefits to society.

One of the issues currently on the agenda of the United Nations is the issue of enhancing the rights of older persons. Within intergovernmental process important steps are taken to document existing infringements of the rights of older persons, and highlight the current status of rights at the national level. There are a lot of issues on the agenda in this regard.

What amounts to age discrimination in today's world? What are the causes of ageism and elder abuse in different settings? How can Governments, aside from legislative measures, prevent age discrimination in all of its forms, including gender discrimination?

There are normative and implementation gaps in legislation, and they need to be addressed. The key documents of the UN on human rights include the Universal Declaration of Human Rights, as well as the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural rights. While the universal nature of these documents implicitly acknowledge the rights of older members in society, none of these documents contain direct reference to older persons.

Almost all human rights instruments fail to identify age as a prohibited ground for discrimination, thus obscuring the discriminatory experiences of older persons. The numerous obligations of states vis-à-vis older persons are implicit in the UN human rights instruments but remain invisible for both Governments and the general public, while the obligations on private sector actors and individuals are not well developed. The standards that offer older persons protection are dispersed through many human rights texts.

The rights of older persons continue to be violated on the individual level as well as institutional level, and violation of rights manifests itself in the form of discrimination: denied promotion opportunities, not given an equal chance during the hiring process, discrimination in health care or access to services. This is an unfortunate practice in many countries.

One of the key issues is how to make implementation of existing laws more effective. There is a question of what steps may improve the legal structure geared at securing the rights of older persons who receive long-term care as well as the rights of caregivers. Enforcement mechanisms in many countries leave much to be desired. It may not necessarily be related to unwillingness of authorities to tackle this issue, but to a combination of factors: lack of funding and lack of capacity.

At this stage there are very substantive discussions conducted at the international level (but behind the scenes) as to whether the convention on the rights of older persons is a desirable outcome. Some other instruments as for instance the idea of the Special Rapporteur on rights of older persons are also considered. We need to find convincing answers

whether those options are viable and effective. The answers convincing for member states from all standpoints.

The intergenerational dimension and particularly intergenerational solidarity in families, communities and nations is truly fundamental for the achievement of a society for all ages advocated by Madrid Plan. The demographic transition and the increases in life span happening around the world means that many adults live longer lives over which they can share knowledge and resources with younger generations. Greater longevity also implies that the number of years separating the young from the old is abound to expand, and strengthening ties through equity and reciprocity between generations becomes not only highly desirable but really, vitally important. Age-related risks are well recognized on both cohorts, younger and older. But rather than emphasizing the differences between the ages, it is imperative to recognize their synergies and growing interdependence and take it into account in public policy formulation and implementation. Promoting intergenerational solidarity contributes to building trust in society and in many ways fosters a sense of interdependence between people that springs from shared interests. It also helps fighting negative stereotypes about both older persons and young people.

The empowerment of older persons as well as positive images of ageing advocated in the Madrid Plan, are important factors that may facilitate multigenerational cohesion in society. Empowerment of older persons is a very attractive slogan but in order not to convey an empty message, one needs to fill it with real meaning and real substance. When ageing concerns are mainstreamed into national development policies, Governments have an opportunity to deal with ageing in an integrated and holistic way.

We should not overlook the issue of vulnerability of older persons. Of course, not all older persons are vulnerable. Quite to the contrary, many of them are quite robust, healthy and actively participate in society. But overall, the vulnerability dimension should not be overlooked. For example, in many developing countries, the ageing population is dominant in many rural areas. Rural ageing often places an enormous burden on scarce household resources and community services and older rural residents are particularly susceptible to poverty and malnutrition. With no earned or pension income, that category may be most vulnerable and dependant on the help of their relative or friends and community.

And here again, the plight of older women may be particularly difficult as they are often denied access to productive assets with highly negative consequences for their well-being.

Commitments made in the Madrid Plan and the Berlin Regional Implementation Strategy and the Leon Declaration adopted at the UN-ECE Ministerial Conference on Ageing in Leon, Spain, have been most important for European countries in charting their course of action regarding ageing.

When we are talking about media freedom and efforts to bring media on board in the context of addressing the rights of older persons, we should not overlook the issue of partnerships and the role of civil society in addressing the challenges and opportunities of ageing. In many countries, civil society organizations were instrumental in implementing the bottom up participatory approach to the policy on ageing.

Social protection efforts undertaken in many countries are geared at providing income security for older persons. But social protection could, and should be, interpreted more broadly, in a very proactive way, defending the rights of older persons and promoting full realization of their potential in society.

Let me again touch upon the issue of empowering older persons to become full and active participants in society. Empowerment process is directly related to the issue of prevention of abuse and neglect. People who are fully aware of their rights who can resort to legal measures to uphold these rights are much better able to participate in society and withstand any attempt of abuse, not to mention violence against them. Of course, purely legislative measures may not be sufficient when we are talking about wider participation of people in society but they represent an important starting point. How the process evolves depends on the ability of all stakeholders to cooperate, to come together as citizens. Careful review of existing laws and regulations for bias or discrimination is also very important. The state has the primary responsibility to ensure access to well-functioning and sustainable social protection systems on equal grounds. But the State alone cannot move the agenda of social inclusion forward. It needs to be done in conjunction with efforts of all other social partners. Only then we can hope for long-lasting outcomes that secure the dignity of senior citizens.

Thank you for your attention.

Marián Hošek, Deputy of Ministry for Labour and Social Affairs of the Czech Republic

Dear Eurocommissioner,
Dear Madam President,
Dear Chairman,
Ladies and gentlemen,

It is an honour and a privilege to welcome you to Prague on behalf of the Ministry of Labour and Social Affairs to this conference taking place as part of the Czech Presidency of the European Union Council and to say a few words by way of introduction.

The Czech Republic chose as one of the priorities for its presidency the topic of dignified, healthy and active old age. The issue of frailty and threats in old age, the theme of this conference, is fundamental for this priority.

The Czech Presidency follows on from the French and Slovenian Presidencies, which emphasised the significance of Alzheimer's Disease and intergenerational solidarity in the context of long-term care. The issue of dignity and healthy ageing is also a joint priority and important topic for cooperation with the upcoming Presidency of the Kingdom of Sweden, for whom we would like to express our full support.

The motto of the Czech Presidency of European Union Council is "Europe without Barriers". In the context of today's conference this motto takes on many new and fundamental meanings. This is for example a Europe without age barriers, without barriers between generations, without barriers in job opportunities, without barriers in the environment and in access to services, opportunities and rights, but also in overcoming barriers between services, professions, perspective, barriers to cooperation at local and central level or the barriers within ourselves, preventing us from achieving the possible.

The present era is exceptional. We are experiencing a period of complicated changes, a period of global economic crisis, rapid technological development, continuing urbanisation and migration, but perhaps also, a calling into doubt of values relating to local community, to our attitudes to old age or family roles. At the same time all of these changes create a context in which each of us will be getting old and in which the number and proportion of the most elderly in our societies will grow.

In this regard it is good to be aware that the experience of old age is nothing new, nor are the individual, relationship or "community" questions associated with it. Respect for old age as part of our relationship to those closest to us takes on the form of the respect we have for our parents and grandparents, which is a value as old as humanity itself. This is a fundamental value of European culture and civilisation and a characteristic of all civilisations.

Concerns over the ageing of the population, which has been going on now for decades, surface over and over again. Life span is of course not only a result of wealth and the growth of society, it is also one of its causes. So the problem is not ageing itself, but rather our concerns and insecurity, our incorrect understanding of the problems and often an unwillingness to adapt services to the ongoing changes and developments. The problem is not the actual need for support and care, but the threat to dignity and values.

I am of the view that one of the fundamental values of old age is not to be torn out of the community. One of the main challenges associated with ageing is therefore the placement and inclusion of old age and ageing into the whole, into the whole of life, into the whole of the person and the whole of their life story, into the whole of links to the community and family and principally into the entirety of the meaning of life. In this regard it is a challenge to remain one strong community, undivided by age, skin colour, gender or any other criteria, the challenge is greater solidarity within diversity and a socially and inter-generationally cohesive society.

This conference and its programme encompass many topics. Their seriousness and complexity are great and their significance continues to grow. The conference's focus points out the need for a paradigm change, a change to the concept of services and policy, including the shift from residential services to community services, from fragmented specialised health care to a focus on empowerment, dignity and the social role of the sick and frail or those with handicaps.

Many countries throughout the world are adopting positive strategies based on acknowledging the diversity of senior citizens' lives and their experience in old age and on the concept of active ageing. And for this a fundamental concept for the adaptation of services and policies is the concept of "age-friendliness".

However in spite of this the prolongation of lifespans is still rather a source of concerns rather than positive changes aimed at adapting services and making positive use of opportunities. It would therefore be desirable to formulate a common positive vision and strategy for active, dignified and healthy ageing in the European Union, which would regard ageing as an opportunity and which would establish specific recommendations for adapting policies and services to an ageing population, and which would not focus only on dealing with the fiscal impact of demographic changes or the extension of working life.

The Czech Republic is one of those countries which has set out on the road to integrating or "mainstreaming" ageing into more detailed policies, even if this road is not always simple or easy.

The National Programme for Preparation for Ageing for the period 2008-2013, adopted by the government in 2008, places great emphasis on the role of local authorities, senior citizen organisations and their supporters and on civil society in general. The Government Council for Senior Citizens and Population Ageing, established in 2006 as a government advisory body, has the chance to become a standard bearer for a new vision, new approaches and new tasks.

Ladies and gentlemen,

There really are many areas in which we can cooperate as member states of the European Union. These certainly include research and education in gerontology and geriatrics, the exchange of experience in providing (socio-legal) protection for those dependent on care, the development of community long-term care, changes to housing, transport and other services and policies for the growing number of frail senior citizens in our societies, Etc.

The motto of the conference and the draft "Prague Declaration" which will be one of the outputs of our discussions is "Commitment and support for meaning in old age". Every need and desire in our lives always has the weight which our humanity gives it. The commitment to meaning, to service, to solidarity and usefulness are definitely among the highest values in human society.

I believe that this important conference will contribute to the debate on the current anchoring and concept of the human rights of senior citizens as part of international cooperation and will furnish a new way

of looking at things, consensus, innovative solutions to many detailed questions and impulses which we all need and expect.

I hope that the conference will strengthen our joint commitment to meaning and commitment to change; our commitment, both individual and shared as well as the political commitment of the institutions and people responsible to specific steps and that our joint discussions will give us strength and enthusiasm in the at times difficult efforts that we make at various levels and during which we perhaps overestimate the differences due to the differing professions and roles in which we operate.

Ladies and gentlemen,

I wish the conference and all of us here present every success, as well as a pleasant and enriching stay in our beautiful capital city of Prague.

I thank you for your attention.

B. WORKSHOPS



1. WORKSHOP

1.1 WORKSHOP:

DECIDING ABOUT THE FORM OF CARE, RESPONSIBILITY FOR DELIVERING CARE, AND ELDER ABUSE AND NEGLECT

Key question: Frail old people in the family. Support of autonomy or permanent care?

CHAIRPERSON: Ruth Paserman [EC]

REPORTER: Gertraud Dayé [AT]

ASSISTANT: Veronika Skypalová [CZ]

Giovanni Lamura [IT]

Lamura G., Melchiorre M.G., Quattrini S., Principi A., Chiatti C., Mnich E., Bien B., Wojszel B., Krevers B., McKee K., Mestheneos L. and Döhner H. on behalf of the EUROFAMCARE group *

“Burden and support needs of family carers of older people”

1. My presentation aims at sharing with you some reflections on the burden and support needs experienced by family carers of older people in Europe.

* The EUROFAMCARE group: Germany: Hanneli Döhner (Co-ordinator), Christopher Kofahl, Daniel Lüdecke, Eva Mnich, Susanne Kohler, Nadine Lange, Kay Seidl, Martha Meyer (Hamburg) and Heinz Rothgang, Roland Becker, Andreas Timm, Kathrin Knorr, Ortrud Lessmann (Bremen); Greece: Elizabeth Mestheneos, Judith Triantafillou, Costis Prouskas, Sofia Kontouka, Vicky Goltsi, Anastasios Loukissis, Katerina Mestheneou; Italy: Giovanni Lamura, Cristian Balducci, Maria Gabriella Melchiorre, Sabrina Quattrini, Liana Spazzafumo, Francesca Polverini, Andrea Principi, Marie Victoria Gianelli; Poland: Barbara Bien, Beata Wojszel, Brunon Synak, Piotr Czekanowski, Piotr Bledowski, Wojciech Pedich; Sweden: Birgitta Öberg, Barbro Krevers, Sven Lennarth Johansson, Thomas Davidson; UK: Kevin McKee, Mike Nolan, Louise Barber, Jayne Brown; AGE-Platform: Ann-Sophie Parent, Jyostna Patel, Catherine Daurèle, Karin Pflüger, Edward Thorpe. Address for correspondence: Dr. Giovanni Lamura, c/o INRCA - Istituto Nazionale di Riposo e Cura Anziani (www.inrca.it), Department of Gerontological Research, V. S. Margherita 5, 60124 Ancona, Italy; Tel.: (0039) 071-8004797; Fax.: (0039) 071-35941; E-mail: g.lamura@inrca.it.

The EUROFAMCARE (EFC) group

Germany: Döhner H. (Co-ordinator), Kofahl C., Lüdecke D., Mnich E., Kohler S., Lange N., Seidl K., Meyer M. (Hamburg) and Rothgang H., Becker R., Timm A., Knorr K., Lessmann O. (Bremen);

Greece: Mestheneos E., Triantafyllou J., Prouskas C., Kontouka S., Goltzi V., Loukissis A., Mestheneou K.;

Italy: Lamura G., Balducci C., Melchiorre M.G., Quattrini S., Spazzafumo L., Polverini F., Principi A., Gianelli M.V.;

Poland: Bien B., Wojszel B., Synak B., Czekanowski P., Bledowski P., Pedich W.;

Sweden: Öberg B., Krevers B., Johansson S.L., Davidson T.;

UK: McKee K., Nolan M., Barber L., Brown J.;

AGE-European Older People's Platform: Parent A.-S., Patel J., Daurèle C., Pflüger K., Thorpe E.

The EUROFAMCARE study (2004-2005):

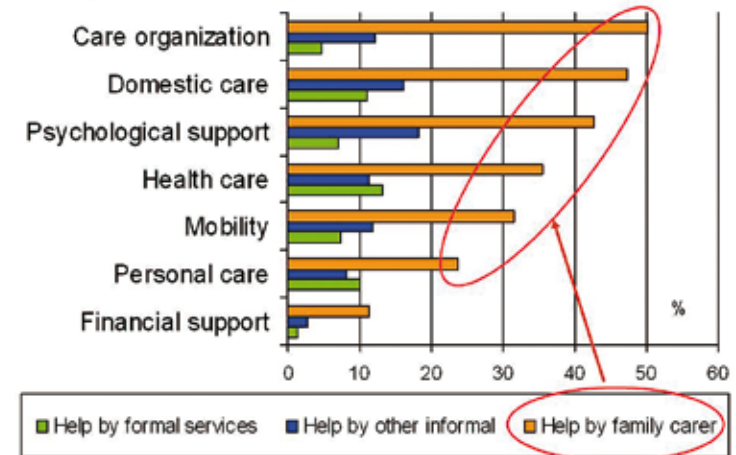
- topic: situation of supports for family carers of older people in EU
- methodology: survey based on 6.000 face-to-face interviews
- web-site: www.uke.uni-hamburg.de/eurofamcare

2. I will mainly provide empirical evidence based on the EUROFAMCARE study, carried out by research teams in 6 European countries and by AGE (The European Older People's Platform), who collected data on 6.000 family carers providing at least 4 hours per week of unpaid help to older people.

3. After an introduction on the issue of family caregiver's burden, I will review some potential risk factors for this phenomenon, before concluding with some final remarks.

4. We have to start by clearly recognising that family care represents, in Europe as elsewhere, the most relevant form of support provided to dependent older people living in the community...

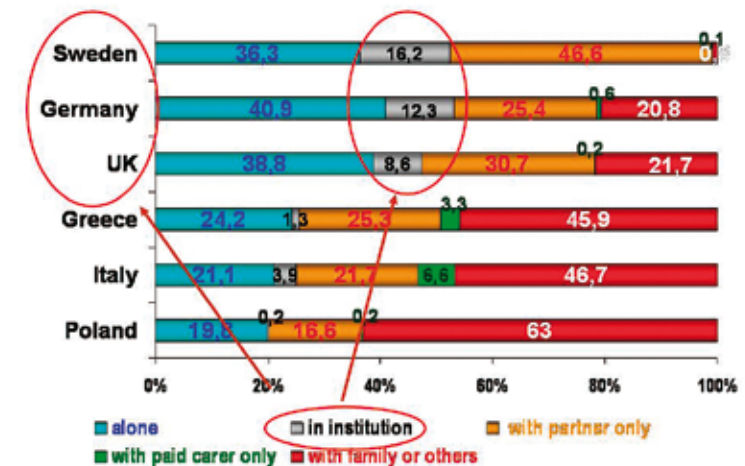
Completely dependent over 65 year old persons, by source of help received for different tasks



5.... as shown by the fact that, no matter which task we consider, help to dependent older people is, by far, more frequently provided by the family, rather than by other informal sources or formal care services...

6.... to the point that family support often continues to be provided even after the older person is institutionalised in residential facilities...







Living arrangements of older persons cared for by families



7.... this being the case especially in Northern and Central European countries, where institutionalisation is more widespread

8. Mainly provided by women, family care is in most cases granted on the background of positive motivations, such as love, affection and emotional bonds, and carers generally derive from it positive feelings...







What factors influence families' decision to care?

							All
emotional bonds / love	96,8	96,3	90,5	96,6	94,1	92,6	94,5
a sense of duty	89,3	73,3	79,5	67,7	91,6	85,8	81,4
sense of obligation towards elder as a family member	91,4	57,4	75,6	73,6	93,7	90,9	80,6
caring for elder makes me feel good	81,5	56,4	61,9	83,4	77,2	84,2	74,0
elder would not wish anyone else to care for them	43,5	45,4	62,9	46,1	53,6	62,1	52,3
there was no alternative	53,2	30,3	46,0	45,5	45,4	64,4	47,6
I found myself caring by chance without a decision	37,8	31,5	61,5	65,3	32,3	29,5	42,7
my religious beliefs	40,0	38,0	22,6	8,2	67,7	24,7	33,9
high cost of formal care	43,8	31,1	30,2	14,8	34,4	45,1	33,5
economic benefits	8,0	4,3	8,7	13,2	8,1	12,3	9,1

9.... as shown by the fact that almost all carers, in all countries, refer to these reasons to explain why they care, and that three quarters of them feel good about their caregiving experience.

10. Sometimes, however, family care represents or becomes in the eyes of the involved caregivers the only solution available (i.e. no longer a "free" choice)...

What factors influence families' decision to care?

							All
emotional bonds / love	96,8	96,3	90,5	96,6	94,1	92,6	94,5
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high cost of formal care	43,8	31,1	30,2	14,8	34,4	45,1	33,5
economic benefits	8,0	4,3	8,7	13,2	8,1	12,3	9,1

11....in connection to a feeling of duty and of obligation towards the older person or to the lack of realistic and affordable care alternatives.

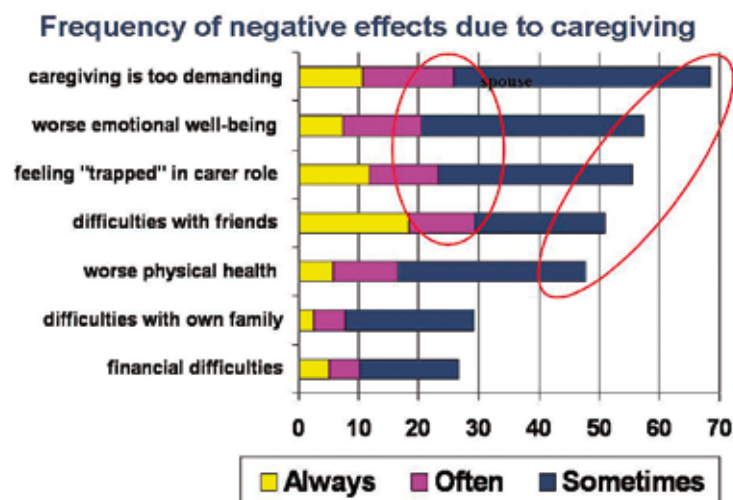
12. For these and other related reasons, family care might become sometimes a stressful, burdening experience...

Carers' burden in the EUROFAMCARE study

Components identified by carers as responsible for a "negative impact" of caregiving:

- negative effects on physical health and emotional well-being;
- difficulties in relations with family and friends;
- financial difficulties;
- sensation that caregiving is "too demanding" and makes carers "feel trapped".

13.... associated, according to what carers themselves report, to negative effects on their physical health and emotional well-being, difficulties in the relations with their family and friends, but also in financial terms, as well as to a sense of loss of control over a situation becoming too demanding and making carers feel “trapped” in their role.



14. Especially feelings of “emotional overload” seem to be quite widespread, and worryingly frequent (i.e. occurring always or often) in the experience of about one out of four carers on average...

15....thus potentially leading, under unfavourable circumstances, to the abuse of the older person who is actually supposed to be cared for.

Frequency of elder abuse by family carers

Different definitions and methodologies in collecting data lead to **divergent findings in terms of prevalence** of elder abuse perpetrated by family caregivers (NCEA 2002). Taking for instance physical abuse:

- 5% (Paveza et al 1992);
- 6% (Pillemer & Suiter 1992);
- 11% (Compton et al. 1997);
- 12% of all callers to a help line for caregivers (Coyne et al 1993);
- 23% of non-spousal carers (Wolf 1996).

16. Different studies confirm this phenomenon, by estimating the prevalence of elder abuse perpetrated by family carers – for instance here referred to physical abuse – in a range between 5% to over 20%, depending upon the definition and the methodology used.

Burden in family carers of older people

1. Family care represents the most relevant form of support provided to dependent older people living in the community (often continuing when the older person is institutionalised).

2. Most people provide family care for positive motivations, such as love, affection and emotional bonds, and derive from it positive feelings.

3. Sometimes, however, family care becomes the only solution available, due to a feeling of duty / obligation toward the older person or the lack of care alternatives

4. For these and other reason, family care might become then a stressful, burdening experience...

5. potentially leading even to the abuse of the older person who is actually supposed to be cared for.

2. RISK FACORS FOR POTENTIAL SITUATIONS OF BURDEN IN FAMILY CARERS

17. Coming now to the risk factors for potential situations of burden in family carers...

18.... it is not surprising that some of them are considered also as predictors of situations of elder abuse and neglect...

Risk factors for burden in family carers

Different studies suggest that risk factors for carer's burden and stress also predict elder abuse (Anetzberger 1987; Compton et al. 1997; Paveza et al 1992; Coyne et al 1993; Pillemer & Suiter 1992), with regard to:

- cohabitation;
- amount of care provided;
- care recipient's behavioural disturbances;
- carer's depression & low self-esteem;
- carers' perception of relationship with care recipient
- carer's feeling about the help received from the (formal and informal) support networks.

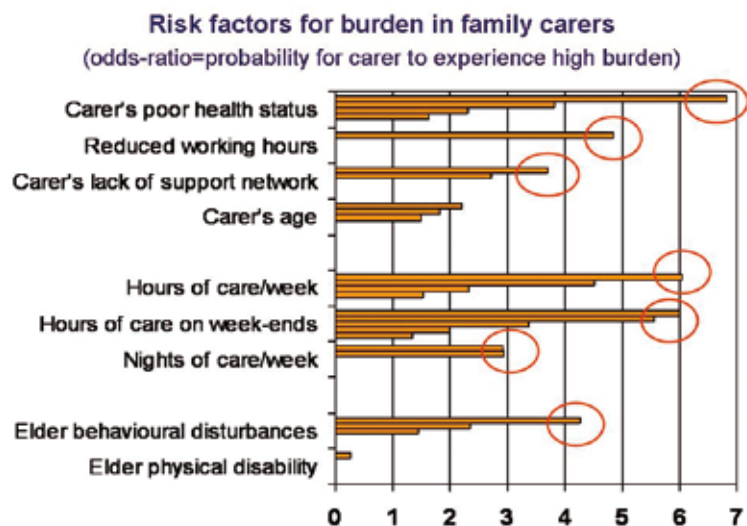
19.... such as for instance when the cared for and the caregiver share the same home; in case of high amounts of care provided; when the care recipient presents behavioural disturbances; when the carer suffers from depression and low self-esteem; when a negative relationship between carer and elder existed already in the past; and when the carer does not feel well supported by existing care services.

Risk factors for burden in family carers

1. Risk factors for caregiver's stress and burden often represent predictors of elder abuse and neglect as well.

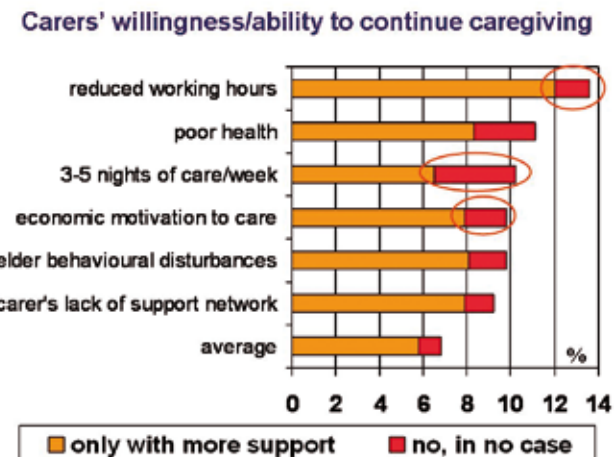
2. The Eurofamcare survey confirms some of these factors, and identifies new ones.

20. The Eurofamcare survey confirms many of these as risk factors for high burden in carers, and identifies some new ones.

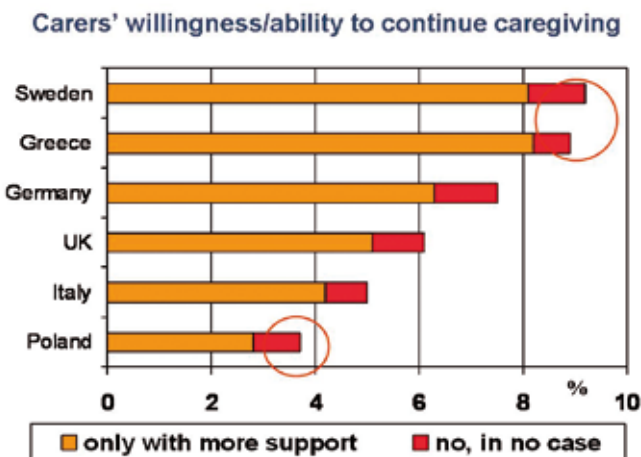


21. The probability for carers to feel overburdened is higher (up to seven times) if the carer's health is poor, when the carers have to reduce their working hours or cannot rely on others' help (to take a break from caregiving or if ill). Relevant predictors are also the amount of care pro-

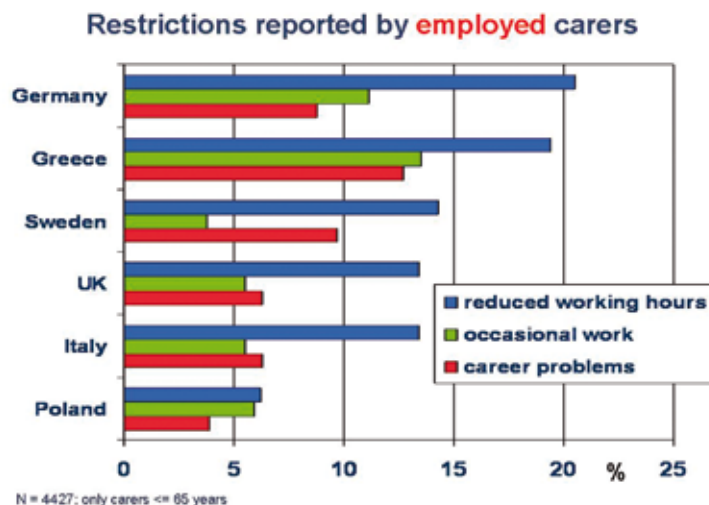
vided, especially if occurring over the week-end and during the night, and the presence of behavioural disturbances in the older person.



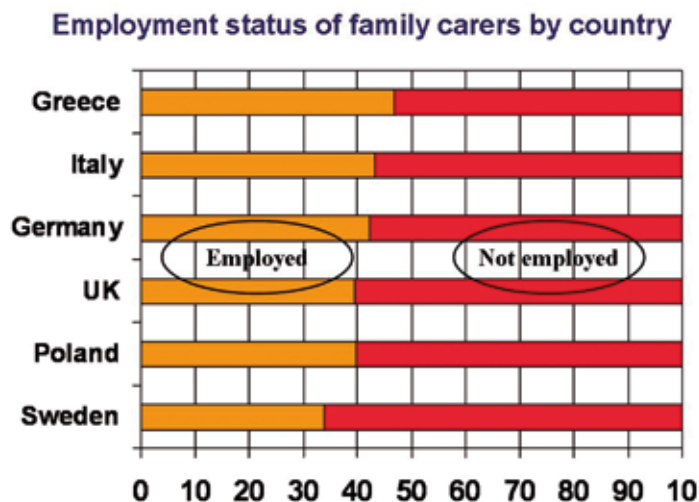
22. Sometimes carers are so overwhelmed, that they are unable to continue caregiving. Apart from health, this risk is higher for employed carers who have to reduce working hours, for not-cohabiting carers who have to provide repeated night care, and when the motivation for providing care is economically driven (for instance in order to benefit from care allowances).



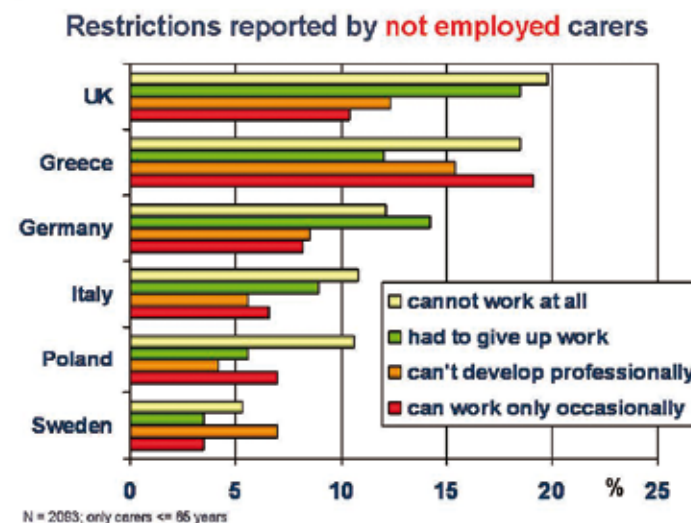
23. The risk of quitting family elder care is unequally distributed across countries, and occurs frequently in nations with very different cultural and socio-economic traditions, such as for instance Sweden and Greece, and less often in a country like Poland, here probably due to preventive factors such as the presence of multigenerational households and strong religious traditions.



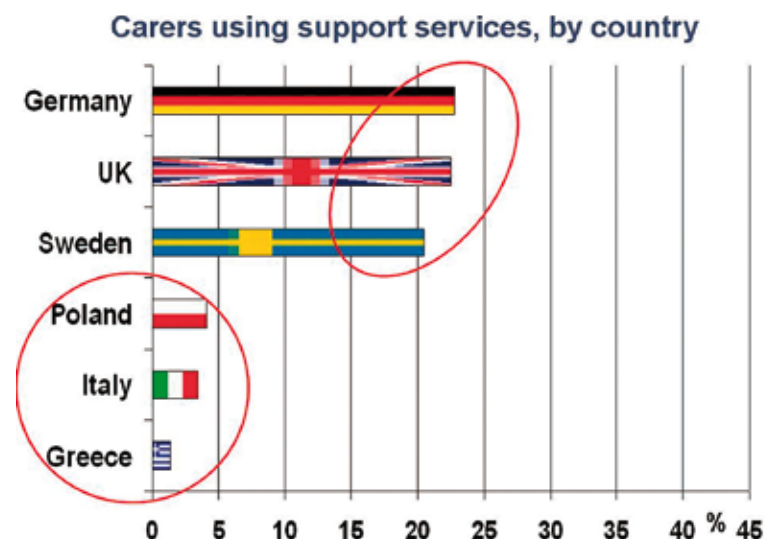
24. The reduction of working hours, as we have seen one of the most relevant risk factors for carers' burden, represents (look at the bar in blue) the most widespread restriction experienced by employed family carers across Europe, reaching about 15-20% of them in most countries (the only exception being Poland), and affecting generally women more frequently than men.



25. In the light of the goals of the revised Lisbon agenda to increase activity rates for women and mature workers, exactly the main providers of family care to older people, this is not at all a marginal problem, since about 40% of all family carers, in all countries, are employed...

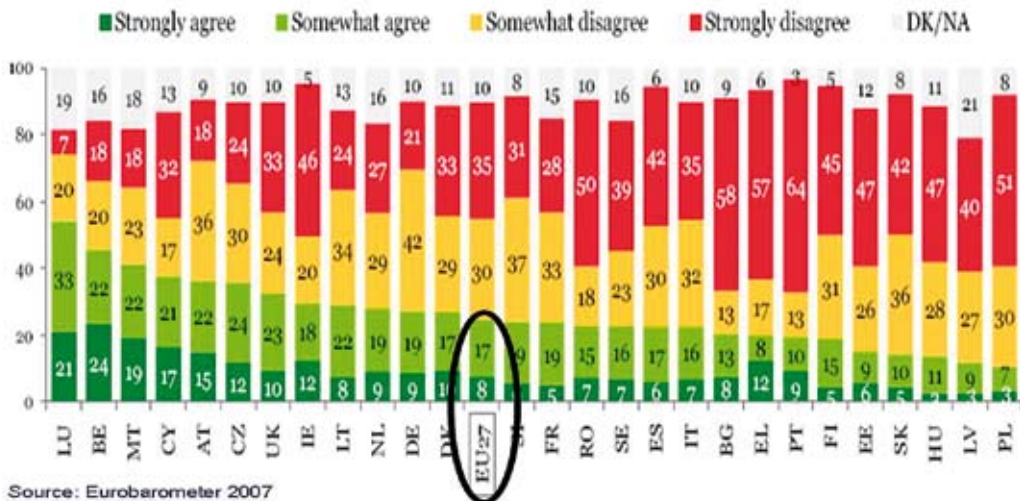


26.... but we shouldn't forget that labour market restrictions are experienced also by not employed caregivers, who due to their care responsibilities are unable to work at all, had to give up work, cannot develop professionally or can work only occasionally.



27. A way to reduce these difficulties and carers' burden in general could certainly be through the use of dedicated support services (such as day-care, counselling, respite care or training). But according to our findings, the use of such services is almost inexistent in Southern and Eastern Europe, and represents a limited reality also in North-Western European countries.

People who have to care for older family members at home receive good support from social services



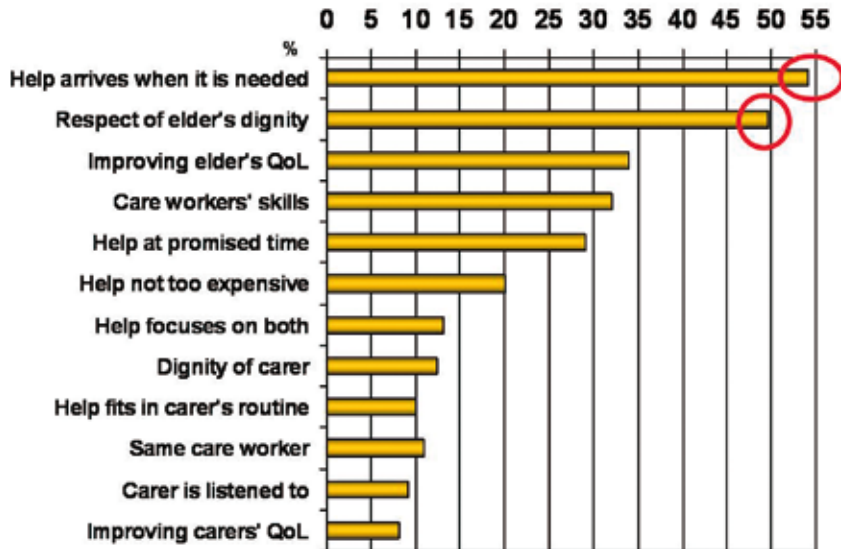
28. And indeed, recent Eurobarometer data tell us that, on average, only one fourth of the European Union citizens believe that carers of older people are well supported by care services...

People who have to care for older family members at home receive good support from social services



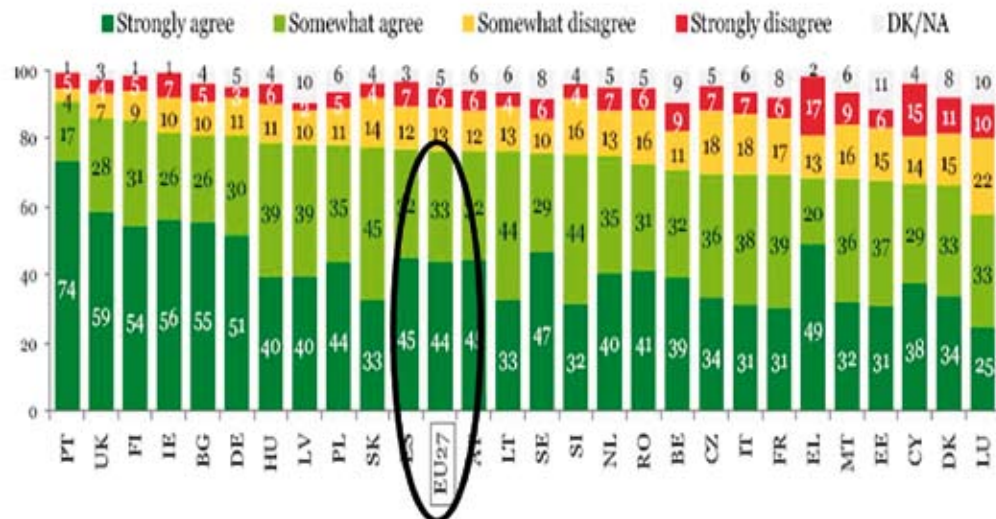
29.... a better situation being recorded in anglo-saxon countries (including the Czech Republic), a worse one in an Eastern European belt going from Estonia to Hungary.

Service characteristics considered most important



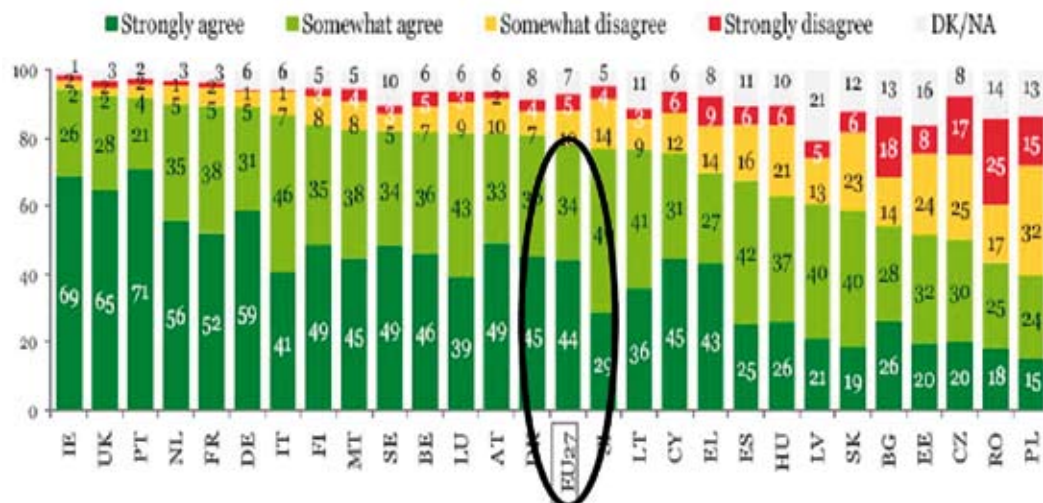
30. How can this situation be improved? It is not only a matter of quantity, that is, to increase service supply, but also and maybe even more, a quality issue. In this respect, the two most relevant characteristics services should have – in the opinion of family carers themselves – are, by far, their timeliness (i.e. to be available at the time they are mostly needed) and, secondly, that care is provided in a way to respect the older person's dignity.

The contribution of older people who care for family or other relatives is not appreciated enough

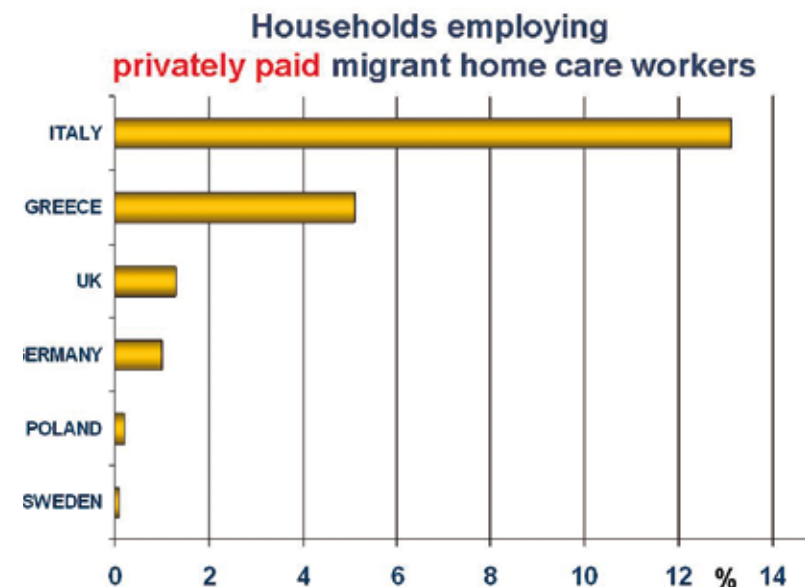


31. What if these improvements do not occur? Well, citizens will continue thinking, as they do today, that the contribution provided by older people to family care is not appreciated enough – almost 80% of European citizens think this way - ...

Older people make a major contribution as volunteers in charitable and community organisations



32.... despite the fact that almost as many believe that older people do make the difference in volunteer organisations, providing a valuable contribution to the overall society. However, the care of dependent older people cannot certainly be a matter of volunteer work only...



33.... and if families continue feeling insufficiently supported by the formal care system, they will try to find their own solutions to tackle the challenge of elder care, hiring for instance privately paid migrant home care workers, as it is already happening on large scale not only in Italy, where I come from...

Migrant care work in Mediterranean countries

Spain: permits for domestic work to foreigners raised from 33.000 in 1999 to almost 230.000 in 2006;

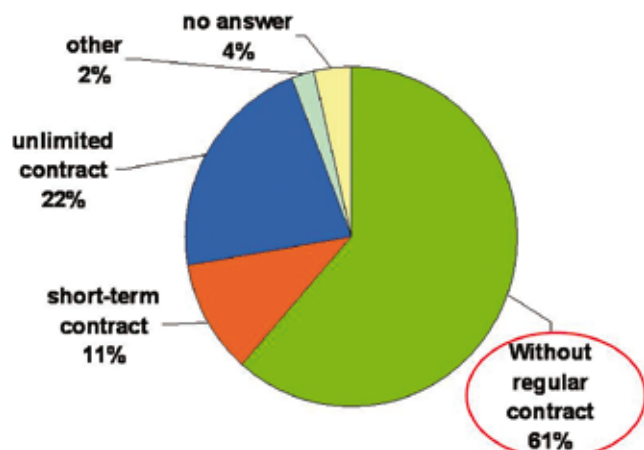
Greece: 2007: 26% of migrants (but 80% of women!) are employed in personal care/household services;

Turkey: "it has almost become normal to employ Moldovan [& Bulgarian] domestic workers in private households" (Kaska 2006 in Suter 2008);

Israel: "About one-third of migrant workers in Israel are women, mostly employed in the 24-hour home care industry" (Kruger 2005)

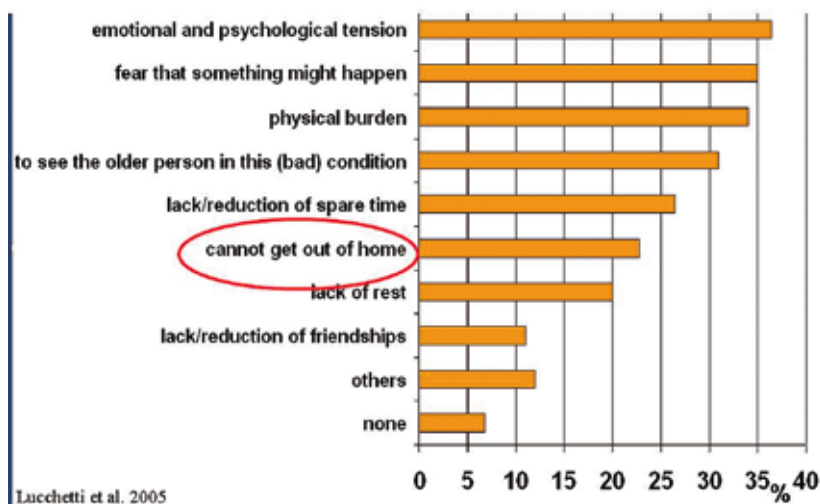
34....but by now in most Mediterranean countries, and increasingly in Continental and Western European countries, too. Although the private employment of migrant care workers - again, mainly women - has certainly helped many families to ease their everyday elder care tasks...

Migrant home carers in Italy by kind of employment contract



35.... we should (however) consider that many migrants are employed without a regular contract...

36. Most burdening aspects for migrant care workers



37.... and experience very hard working conditions, with very little spare time and freedom, almost one out of four reporting they can hardly go out of the home in which they provide elder care.

Care drain risks in migrants' home countries

- **Migrant women's left behind children:** well-off but socially deprived, missing maternal support & cared-for by grandmothers



38. Furthermore, we shouldn't forget the care drain risks in the migrants' countries of origin, reflected by the dramatic stories reported by the children of migrant women working abroad, whose left behind offspring are often economically better off but socially deprived, lacking maternal support and taken care-for by already frail grandmothers.

Care drain risks in migrants' home countries

- **Migrant women's left behind children:** well-off but socially deprived, missing maternal support & cared-for by grandmothers
- **Mental illnesses of migrant women returning home** after long years of isolated care work



39. Or also the mental diseases affecting migrant women returning back home, following a very isolated, unhealthy life as care workers abroad.

Care drain risks in migrants' home countries

- **Migrant women's left behind children:** well-off but socially deprived, missing maternal support & cared-for by grandmothers
- **Mental illnesses** of migrant women returning home after long years of isolated care work
- how much **educational & training costs** have been saved by "destination" countries and borne by "sending" countries?

40. At a macro-level, we shouldn't either forget the huge amount of money saved by nations benefiting from care migrants, whose training costs have been borne by their own home countries...

Care drain risks in migrants' home countries

- **Migrant women's left behind children:** well-off but socially deprived, missing maternal support & cared-for by grandmothers
- **Mental illnesses** of migrant women returning home after long years of isolated care work
- how much **educational & training costs** have been saved by "destination" countries and borne by "sending" countries?
- **sending countries are themselves becoming receiving countries** of migrants from poorer/closer regions to fill the new care gaps

41.... paradoxically starting to become themselves the destination of migration flows from other nations, to fill the care gaps left by their own citizens working abroad.

Conclusions

Shifting burden and exploitation from one vulnerable group to another: from dependent older people to family caregivers, to migrant care workers and their home countries?

Or preventing this phenomenon by investing enough resources in intergenerational solidarity and long term care?

Let's ensure a decent life to dependent older persons and their families, without trying to solve internal care shortages by "plundering the future of resource-poor nations" (Anonymous, 2008).

42. In the light of all this, we should really start asking ourselves – and those who think of this as an easy and cheap solution to the elder care issue – whether we are not running the risk of simply shifting burden and exploitation from one vulnerable group to another (from dependent older people to family caregivers, to migrant care workers and their home countries), rather than preventing this phenomenon by investing an appropriate level of societal resources in intergenerational solidarity and long term care, to ensure a decent life to dependent older persons and their families, without trying to solve internal care shortages by "plundering the future of resource-poor nations".

"Responding to Elder Abuse and Neglect"

Background & introductory comments

Thank-you very much for inviting me to this conference in the beautiful city of Prague; it gives me great pleasure to be here. As there is only a little time for us to make our presentations I will try to be as brief as possible and will commence straight away. By way of introduction, it is necessary to acknowledge first of all that this is a global phenomenon; elder abuse and neglect are found across the world and up until now we have not found a country where it does not exist. If we look at historical perspectives, there are references to abuse and neglect of older people in documents and literature dating back over the centuries (an example of this can be found in Shakespeare's King Lear, which concerns the dysfunctional relationships between a father and his daughters). However, abuse and neglect as phenomena have been quite recently recognized; in many countries it is only in the last 2-3 decades that there has been recognition of the problem although it is fair to say that there has been increasing concern about the issue since that time. There are a number of reasons for this increasing recognition and concern. These include the following:

- Community care & systems of de-institutionalisation
- Demography and an ageing population
- Medical advances & technology resulting in more people living longer
- Advocacy and rights (human and citizenship) focus in recent decades
- Changing social structures
- Additionally, we also need to recognize the importance of professional recognition of the issue as of concern. This is similar to the situation of child abuse/protection, where it was medical clinicians who first raised concerns about this form of abuse (in the 1960s and early 1970s), whereas for domestic violence it was activists in the 'grassroots' feminist movement of the 1970s who initially identified violence and abuse directed towards (younger) women. In relation to elder abuse and neglect it was not until the 1980s, within a European context, that professionals began to draw attention to the phenomenon. This identification

is important, as it has influenced what has subsequently happened in the development of responses to elder abuse and neglect and the lack of and delay in awareness by the wider public of the issue.

General points

There are a number of general points that need to be considered in relation to the area in general. Firstly, there are definitional issues that we need to be aware of. There is no agreed universal or standardized definition at present. As I have previously said elsewhere, this may not matter too much and there could be different definitions in use by different stakeholders (legal and policy-makers, practitioners, researchers and so forth), although these need to be explicit and acknowledged by the different constituent groupings/parties. Secondly, there is still a general lack of awareness of abuse in many countries and this can lead to difficulties in detection & identification of abuse and neglect by practitioners as well as the wider public and older people themselves. The concept of abuse and neglect is both under-developed and under-researched and the recognition of the phenomena has followed different trajectories and histories in different countries. We have seen the development of a number of NGOs working in this area in recent years and in many places they are undertaking important work in raising awareness and lobbying for change. However, there is still a critical need for more education & training at a range of different levels, for the general public, as well as for practitioners and students in human service fields.

Issues in responding

We must also consider some further issues in terms of decisions about responding. Firstly, is elder abuse and neglect an aging issue? Is this something that only happens due to ageing? From what we know so far, this appears to be unlikely (for instance, domestic violence in later life may be a continuation of a long-standing pattern of behaviour). Is it rather a complication of caregiving? Given that situations of abuse and neglect may occur outside of a caregiving context, this does not appear to provide an answer either. If we utilize a family violence perspective, then our focus may be on systems of prevention, protection and punishment. However, even here there are apparent tensions between a service & welfare orientation on the one hand and orientation towards justice &

criminalization, on the other. These aspects are likely to require further attention in future.

Protection & prevention

Prior to considering interventions and responses in a little more detail, it is necessary to consider the concept of protection. Firstly we need to recognize that protection may be either

- Preventive: to prevent something from occurring
- Reactive: after an event has occurred but to prevent it from happening again

There are a number of protective actions that may be undertaken. These include rules, regulations & laws, policies, procedures & guidance. Action taken to protect individuals generally includes some attention to systems of risk reduction. Issues of vulnerability are also an important consideration, this may relate to vulnerability of the individual themselves, or the vulnerability and potential risk of harm to others. In terms of levels of prevention, there are 3 types:

- primary prevention: community-level action to support and prevent harm
- secondary prevention: individual level action to reduce risk of harm
- tertiary prevention: individual level action to prevent re-occurrence of event

Intervention types

There are a number of different types of intervention that might be used in situations of elder abuse and neglect. Some of these are as follows:

- Practical: for example, domiciliary support at home
- Legal: for example, use of legal system to prosecute for theft in financial abuse
- Therapeutic: for example, couple therapy to improve relationships
- Focus on protection & safety: to keep the victim safe & prevent harm
- Focus on autonomy & empowerment to enable the victim to survive
- Victim orientation: strategies to assist the victim
- Abuser orientation; strategies to assist the abuser

- The choice of which intervention to use depends on the situation and the type of abuse that has taken place, for example, practical assistance to support the individuals involved may be used in situations where the abuse/neglect is due to caregiver stress. However, we do not yet know enough about which strategies of intervention work best and are most effective for which situation

Principles of Assessment

In general terms, prior to the development of any intervention it is necessary to undertake a comprehensive assessment of need of the individuals involved. Although this assessment should be holistic and consider the whole person and their circumstances, it also needs to be abuse-focused. It is also necessary to determine if this is to be an assessment or an investigation, as the latter tends to be rather inquisitorial and adversarial in nature. In any event, the resulting care plan that is developed with the individuals concerned should incorporate elements relating to safety planning and how to meet any needs for protection. In addition to assessment of risk inherent in the situation, consideration must also be given to the subsequent management of risk(s). The concept of 'protective responsibility' developed by Stevenson and Parsloe may also assist in relation to this, as they suggest that practitioners/professionals need to be aware of the need to act responsibly in relation to service users and that at times this may include a need to take action in order to afford sufficient protection for individuals.

European perspectives & responses

When considering what has taken place in relation to elder abuse in recent decades we need to acknowledge that this is a remarkably diverse region

in social, cultural & economic terms. Additionally, in many countries in the region differing meanings & understandings of elder abuse and neglect have developed. If we consider a 30 year time span across Europe, we can see that there are differences in terms of legislation & policies and intervention strategies that have developed and there has been an increasing amount of research & publications concerning elder abuse and neglect, although in some countries, this has been a comparatively recent development. Looking at the sorts of responses that have

developed across the European Economic Area, we can see the following types of developments:

- France & Italy: Helplines
- Germany: model projects & helplines
- Belgium: intervention centres for elder abuse
- Holland: Awareness raising campaign, interventions centres (NGO led)
- Ireland: National plan, senior caseworkers
- Norway: National Centre for information and research on Violence and traumatic Stress, special units in 3 areas
- Spain: professional guidance, screening & assessment tools
- Italy: helplines, heat-wave action, support tutor
- England & Wales: policies & procedures (recent review), campaigns
- Scotland: Specific legislation (Adult Support & Protection Act)
- Czech Republic: Helpline
- Poland: recent research, violence units
- Whilst a number of countries have been working positively to develop responses to abuse and neglect there are several (accession) countries where work/interest in the topic is comparatively recent.

Future possibilities

In order to develop the field further, a number of strategies could be employed. Several of these will require research to be undertaken. We need Intervention studies in order to ascertain which techniques of intervention work best and in which circumstances. This could include the development of model projects for different interventions, with appropriate evaluation of these. We also need to undertake research on effectiveness & impact, not just of interventions but also the impact of abuse and neglect on individuals. The establishment of specialist teams, with specially trained practitioners is also worth considering, but it is now clear what model for this might work best. Of course, in addition, we need to ensure that there is a focus on individualised approaches, tailored to the needs of particular individuals as far as possible. And the potential for development of European-wide approaches is also some-

thing we need to consider carefully and pay attention to in the future. THIS WILL REQUIRE FURTHER

research & development and international collaboration, which is one of the values of this European-sponsored conference.

Thanks very much for your attention and for listening today. Please do make contact with me at the following address, if/as necessary; my details are as follows:

Workshop Report

DECIDING ABOUT THE FORM OF CARE, RESPONSIBILITY FOR DELIVERING CARE, ELDER ABUSE AND NEGLECT

Key question: Frail old people in the family, Support of autonomy or permanent care

The Workshop highlighted that there is a continuum from a supportive, care giving family to an abusive family, a risk factor for abuse. The panelists highlighted

- a) different policies that could be used to ensure that families move more towards the supportive side of the spectrum e.g. support to carers and
- b) what could be done to identify earlier abusive situations (e.g. DP)

More research is needed to find out when the family develops from the one to the other, and what could be useful preventive interventions.

- frail old people in the family, Support of autonomy or permanent care:
- support of autonomy should be represented as an alternative to permanent care

Focus should be on the support of care recipients and of careers

The relationship between care recipients and careers is in the majority an intergenerational relationship. German Charter of Rights for People in Need of Long Term Care and Assistance can be a tool to detect elder abuse. The Charter of Human Rights is to be the basis for defining quality of care. When developing quality indicators it is important to combine perspective of careers and perspectives of care recipients.

BURDEN AND SUPPORT NEEDS FOR FAMILIES CARING FOR OLDER PEOPLE:

Care within the family represents the most frequent form of support, also after institutionalization. Family care is based on positive feelings, when there is no alternative it becomes a stressful experience and this might lead to abuse. Past negative relationships are also a risk factor.

Family career must have the feeling of being supported by professionals. Outside help must be provided when needed and with respect for care recipient and career. Privately paid migrant home care workers. Their rights must be respected with regard to contract, payment and working hours. Drain risk in the migrants countries – where children and own old relatives might suffer.

Risk of shifting the burden from one vulnerable group to another : from dependent older people to family care givers and then to migrant care workers and their home countries.

How to identify Elder Abuse and Neglect in the family, methods of monitoring and dimensions of responsibility:

Not to see only the older persons as victims – careers and care recipients, may be the victims of abuse. Challenges to detect elder abuse and neglect: abuse is hidden, seen as a stigma, definition is not exact, there is a lack of confidence to state it on the side of professionals...

Responses: legal provisions – but also practice experience and expertise to detect abuse must be developed

Older Persons themselves must be involved in fighting elder abuse, in order not to be paternalistic, having a pressure group activity.

Solidarity conflict and ambivalence:

Intergenerational relations are changing with the changing family structures. There is a need to re-negotiate intergenerational relations.

Risk of having a too harmonious solidarity model. There is ambivalence, there are mixed feelings – they may lead to abuse.

Internationally the legal family obligation to provide care varies, but whether care is provided is also a question of closeness. A certain degree of filial obligation is generally recognized.

Emotional support is stronger than the instrumental and financial support.

Elder Abuse as a family Violence issue. Toxic family environment:

Elder abuse as a family violence issue. The key objective is preventing violence before it occurs. Should Elder Abuse be more closely integrated in other programs of family violence?

Identify similarities and differences of elder abuse and other forms of family violence. There are overlaps. Then identify risk factors – not all are shared between elder abuse and family violence. Public Health approach: interventions should target all forms of violence – most interventions do not target shared risk factors. More research is needed into shared risk factors and effectiveness of shared interventions. Elder Abuse must not be seen as an issue of ageing, it is a complication of care giving, and it has to do with ageism. Primary prevention is an issue of public health – types of interventions on all levels, from practical to legal therapeutic, focused on protection and safety, autonomy and empowerment, it might be victim-oriented or abuser-oriented. Principles of Assessment: must be holistic but abuse-focused, with the principle of protective responsibility, respectful approach.

Intervention strategies and techniques in Elder Abuse and Neglect:

First contact of victims are often general practitioners. They should be given detection tools.

1.2 WORKSHOP:

Identification of health demands and continuity of care

Key question: Basic concept of Long Term Care (LTC). Hope or fiction?

CHAIRPERSON: Jan Jařab [EC]

REPORTER: Barbro Westerholm [SE]

ASSISTANT: Karel řvanda [CZ]

Zdenek Kalvach[CZ]

“Geriatric syndromes – a way to better understanding and clinical intervention of frail geriatric patients beyond the disease-model.”

Many health problems of geriatric patients aren't explicable well enough within the disease-model, a concept that functions sufficiently well with younger patients. Even the mutual potentiation of several seemingly banal diseases within the multi-mortality creates a new quality of the functional distress. Moreover, involution changes decondition and other biological and non-biological factors take place. Especially with frail geriatric patients with serious disabilities, not even a detailed list of diagnosed diseases specifies the nature and extent of the functional distress, patients'health needs and risks, and how demanding the care of the patients will be. This can seriously disrupt the continuation and quality of the care. A single-track interest of physicians in "diseases" doesn't often correspond to the problems of the sick suffering from multi-cause difficulties, while this approach may even worsen the problems. The solution can be found in the so called "geriatric syndromes" that describe multi-cause chronic and function-serious (interfering with common-life activities) health problems, which have no simple causal solutions, and therefore call for a multi-specialisation approach (B. Isaacs). Multi-cause geriatric syndromes often relate to the phenomenon of the geriatric frailty, and, historically, with the so called geriatric giants. These include, for example, the instability syndrome connected with falling, anorexia syndrome connected with the loss of weight, or hypomobility syndrome connected with decondition and sarcopenia. The European Commission research project K4CARE

worked, for example, and among other things, on the defining of geriatric syndromes.

Lars Anderson [SE]

“World without LTC institutions: challenge or fiction?”

Long-term care (LTC) is receiving increased attention as an ageing population is expected to increase the demand for long-term care services and hence increase public expenses. In 2005, long-term care expenditure amounted for about 1 percent of GDP and 9 percent of total health spending across OECD countries. OECD has projected the expenditure to reach between 2 percent and 4 percent of GDP by 2050. The image of a healthy third age has taken over the gloomy picture of an old age, and although health improvements have been reported in new cohorts of people in the third age, trends in severe disability among the oldest old do not show a consistent decline. Various measures such as improved level of living, health promotion, intermediate housing, information and communication technology (ICT) in long term care are all excellent in their own right. However, their influence on the need for long-term care be it in institutions or at home is limited. Long-term care for frail or disabled elderly people will always be needed, and a major challenge for Governments is to come up with solutions as to how the demand for LTC workers can be satisfied.

Workshop Report

The introduction linked to the Slovenian Presidency meeting a year ago where it was stated that “Understanding broader aspects of Intergenerational Solidarity is a prerequisite for successful tackling actual demographic issues”. Europe is ageing and family structures change. We have the “sandwich women” who are pressed by the needs of children and teenagers on one side and frail older family members on the other. Family members may be spread geographically preventing daily contacts. Some older people do not want to be cared for by family members and prefer care offered by persons not related to them. Thus the needs of older frail people have to be met in a variety of ways.

Long term care in the future might be costly in the future. Therefore both from a human point of view and from an economical the EU

has to make use of the 2012 year on active ageing. There are already action programs on Healty Ageing developed both by the EU and by AGE / Older People s Platform which can be used. Here organisations like the ones representing older people can be a resource to be used. They can reach a vast number of older people at their meetings and other activities.

It was underlined that "Intergenerational solidarity should be mainstreamed in the flexicurity concept and implemented in each of its four componets. A red thread in the discussion was that self-determinations should be respected in all walks of life and paternalism avoided. People must dare to become old and know that their self-determination and dignity will be respected and that their needs will be met.

The question "Why we need concept of geriatric disability" was put forward. The source for this topic is the need of measurement tools for medical conditions, psychological, social and spiritual status of elderly people. Long term care teams for different professions must have a common language in order to collaborate and meet the needs of the elderly person. This a challenge for future research and the concept of geriatric disability is a practical tool for above mentioned functions.

The risk of overtreatment of frail elderly persons was brought as well as the evaluation of the needs of the elderly person. The list of diseases does not decrive an older persons health state and functioning. This is very individual . Frail older people with multi-morbidity can describe themselves as healthy or in very bad health. Rehabilitation of disability is a neglected area. Long term care for frail and disabled people will always be needed in the future.

Contrary to other arenas it is almost impossible to make prognosis on the needs of long term care in the future. It depends on whether we find a remedy for dementia and how we can prevent other health problems in the elderly. It is also almost impossible to assess the individuals choice beforehand. Practically all people want to stay in their won home as long as they feel healthy. However, for many among the oldest old there comes a time when the question of a move to an institution is not so much of a choice as a necessity.

Finally we should provide a long term care which grants older people to live with dignity while maintaing the hgihgest level of functioning, regardless of the setting in which care is provided (WHO 2000).

1.3. WORKSHOP: MEDIA, PUBLIC OPINION, AND OLD AGE

Key question: Influence of the virtual second life to societal attitudes towards the elderly. How can these attitudes be changed?

CHAIRPERSON: Gordon Lishman [UK]

REPORTER: Petr Wija [CZ]

ASSISTANT: Lada Habrcetlova [CZ]

Renata Sedláková, Lucie Vidovi'cová [CZ]

"Media Construction of Reality representation of Old People and Old Age in the Czech Media"

Media are key agents of social construction of reality and they participate in the process of ascription of meaning to old age and older people. How media represent ageing, old age and older people? The image of old age drawn by media is in general evaluated as negative, stereotypical and unfavourable. However, not many sociological studies are actually devoted to provide up-to-date insight into the media praxis. Paper will present findings of the second wave of the study of news coverage of three Czech national TV-channels and main dailies. It compares results from the analysis of news issued in year 2004 and 2008 (more than 8000 pieces of news each year were analysed). We found out that older people are underrepresented in terms of the amount of information as well as its variability. In the quantitative part of analysis we concentrated on topics covered by analysed news and its framing. Most of the news is connected to the criminality, politics and economy topics and most of them had features of infotainment and soft news. We have analysed the language of the news, labels used for signification of older people and main attributes connected to old age and ageing. Abusing of chronological age as a self-explaining category was also very common. Discussion about the function of media as a social exclusion tool, as agent contributing to discrimination of old people and possibilities to influence the journalist praxis is part of the lecture.

Lucie Vidovičová [CZ]

„Demographic alarmism, ageism, and media in the perception of older people”

My lecture presents the concept of demographic panic, also called demographic alarmism, a definition of raising concerns about the future social development on basis of the changing demographic structures - when the number of senior citizens is rising while the number of newborn children and youth is falling. These concerns are usually spread via the mass media, and, therefore, their impact has broad social and economic consequences. It was said that these concerns are, into certain extent, unsubstantiated, because they rest on certain speculative assumptions and long-term prognosis, while their effect on the public and often also on the creation of policies is immediate. The degree of demographic panic can be sociologically measured by help of indicators such as the fear of the future, exaggeration of the number of elderly people in a society, and, last but not least, the ageistic prejudices towards the seniors. At the same time, the role of the media in this process is ambiguous. The media reflect the overall social climate, but they also serve as means by which these prejudices are ventilated, and thus are spread and gain firmer ground in a given society.

As was found in the survey called "The Nature and Prevention of the Elderly Discrimination in the Czech Republic" (Zivot 90, MU Brno 2008), the elderly perceive the mass media to be not only the promoters of the demographic panic, but also the source/cause of the seniors' inactivity, the source of the bad behaviour towards and discrimination of the elderly, and the cause of aggression, estrangement, decline of morals and disrespect towards the old age. According to the accessible data, the elderly form the most loyal audience and are the most loyal readers, while they are by far not the most satisfied ones due to, into a large extent, ageism and demographic panic spread by the media.

Soňa Hermochová [CZ]

“Display of old age in movie ‘2030 Abstand der Alten’”

There are three films (each 43 minutes in length) entitled "Hostages", "Life Underground", "Secrets of the Desert", which are a kind of combination of politicians' official statements and the media and fiction.

The trilogy follows the fate of Swen Darrow, who observes the cruel fate of individual senior citizens and tries several times to actively intervene, of course without success.

The story is set in the period 1989 - 2030 where the present is represented by actual statements and opinions put forward at public presentations; future years point out possible developments resulting from the statements made. We should note that the "alternative" development is presented as unhappy, indeed terrifying, and its main purpose is to point out certain difficulties and name certain potential risks of the current "unbalanced" view of the older generation reflected in all related aspects of our lives.

More than one quotation from the film will undoubtedly give Czech viewers a sense of déjà vu. This is mainly the shifting of the pensionable age, the repeated statement that increasing life expectancy will lead to an increase in the number of senior citizens in society and so on. These demographic developments mean that society must find an appropriate reaction and leads to expectations and the establishment of institutions which would react to the needs of the "elderly" for example in public transport, leisure time, health services etc.

In this part of the fictional documentary the German phrase the M-factor is used, with different meanings: Mitleid Faktor (Compassion), Mord – Faktor (Murder), Minimal – Faktor (Minimum cost outlays for senior citizen care).

Several "heroes" pass through this documentary; their life stories always underline and illustrate a certain issue with the "ageing population" like for example the story of a man who worked hard all his life, lived modestly, but whose wife fell seriously ill after he retired. Her treatment was so expensive that they had to sell their home and following her death the pensioner found himself in prison with others for stealing from a pharmacy because of the high cost of quality, effective medicines.

The official view of these states that they should have been insured, but of course those affected are already of an age where this is impossible....

This story occurs at a time which is characterised by the line "our pension is too high to kill us, but too small to live on". This is a time when one pensioner in three is living below the poverty line.

At this time Swen Darlow is living underground (2nd part of the trilogy) and around individual lives in which he tries to actively intervene; it documents the harshness of society in relation to senior citizens.

At this time "firms" are established to offer, mainly to richer senior citizens, a wide range of services in their centres - health, social, cosmetic, sporting, cultural and so on. A firm by the name of Pro Life comes to the fore.

On the other hand many senior citizens get into serious financial difficulties - the payment of pensions is delayed - and many therefore end up in special prisons for senior citizens over 65 years old, where they must work to pay their lodging (at this time one pensioner in eight has committed an offence).

Pro Life also founds retirement homes in Northern Africa. At this time an investigative journalist begins to take an interest in Swen Darlow, who is still living underground and is on the trail of various scandals which he wants to bring to light. She follows the fate of senior citizens who do not have enough to live an independent life, become homeless or live with their children and grandchildren in multi-generational families. But of course this is not possible when the senior citizen needs constant care not covered by insurance.

Pro Life offers senior citizens contracts to live in luxury apartments - but of course as soon as care for them becomes financially more demanding and exceeds the financial benefit from their pensions, they are moved into the worst possible conditions and under pressure from the staff often sign euthanasia agreements.

The journalist documents all of these stories, and wants to bring them to light, but is subjected to threats, while those who were to confirm her findings avoid her or even end up dying.

The conclusion of the third part "Secret in the Desert" sounds like a warning: "this has not happened yet, but it could".

The whole film cycle has as its aim to awaken and arouse the interest of the public, specialists and politicians in an area in which many steps are without concept, which support an overall atmosphere of admiration and high acceptance of youth, health, beauty, wealth and success and lack of respect for the elderly. Examples of this view are innumerable in our society as well - incidentally "eyewitnesses" will undoubtedly remember several "waves" of such episodes from both recent and earlier history - whether it be the Hitlerjugend or the period characterised by slogans like "Brno is led by youth" or "we are the new youth, Gottwald's youth!". The present is no doubt not so dramatic, but nevertheless we are witnesses to the fact that people over 40 or 50 have greater difficulty in finding work, fashion is focused on the young, there are problems with health payments for senior citizens, etc.

If we wish to influence this trend, the option exists to influence children's views of senior citizens both in the family and in schools, e.g. in the proposed teaching of ethics. Of course even where senior citizens meet, in clubs or at other social occasions, it would be appropriate to point out behaviours which can generate negative attitudes to senior citizens - we have often been witnesses to such situations. Intervening in the atmosphere of society is not easy, but it is possible at every level: Mini - family level; midi - school, civic association, groups and clubs; maxi - the media and politics. Each of us can use one of these levels to influence everyday life, and it remains true that the future is what we make for ourselves. Without doubt we have a long road ahead of us and many tasks in front of us, but if we do not try, but give up at the beginning, we may find that the fictional documentary is only a pale reflection of reality. It is important therefore to have courage, to encourage one another and to take note of even the smallest success. We do this not only for ourselves but also for our children and grandchildren who - we trust - will themselves become senior citizens.

And the trilogy which we are discussing is certainly about motivating individuals to take action. Not only that it notes what gives rise to certain tendencies in society and emotively models risks and critical scenarios in the development of the whole of society and in many respects causes a certain "eye opening" which really must apply to all of us.

Workshop Report

Why are the media important?

ARGUMENTS:

- The media have an increasing impact on public opinion
- Demographic alarmism has an impact on specific negotiations, and people's lives, including the identity of older people
- Demographic alarmism reduces the life of the elderly and in old age
- The economy, health
- Seniors are more subject than object
- Alarmism creates a tension between
- Media as a source of solutions to the problem, identifying the problem (agenda setting, topic selection)
- Media get into public life (Second Life)
- Media as a source of information, but are not always available (financial, design, form) seniors
- They are important for the accessibility of services, awareness of the rights and dealing with situations
- Negative visions, expectations become self-fulfilling prophecy
- Media can be a source of education and positive examples
- In case of problems the company is looking for a common enemy and culprit, which connects the second most
- Media present important aspects (such as the feminisation of old age, intergenerational relationships and the heterogeneity of older people)

SOLUTION:

- Communication with the media and journalists
- More research application
- Prevention of negative interpretation of demographic data offering positive options and examples
- More implementation experiences of older people, their own views and perceptions

- The need for pressure from the bottom
- Send press releases and more to communicate with the media
- Search for themes that connect generations
- Encouraging the media to present the events from multiple angles, including optics seniors

1.4. WORKSHOP: DEVELOPING AN EXPLANATIONS OF ABUSE

Key question: Current UN elder abuse typology enlarges / develops? Why – What?

CHAIRPERSON: **Halina Potocka [PL]**

REPORTER: **Susan B. Somers [USA]**

ASSISTANT: **Klára Cozlová [CZ]**

Gabriele Walentich [DE]

“Financial abuse, practical examples: the view of a prosecutor”

Elder abuse is “a single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person”. This definition of the WHO is now in common use in many parts of the world (WHO World Report on Violence and Health, 2002: 126).

We know that in addition to other categories of abuse of older adults, e.g., physical, psychological, sexual abuse – cases of financial/material abuse of the elder persons, the illegal or improper use of funds or resources from an older person happen as well. We also know that financial abuse can take many forms and can span a broad spectrum of conduct. But we know little about the incidence and prevalence of this issue.

Statistics - e.g. the German Police Crime Statistic - do not provide information about victims 60+ for every crime category. Aside from (aggravated) murder and robbery (mostly of the handbag) elder people 60+ are proportionally seldom recorded as being victims.

From this it follows that just few cases of financial abuse are reported to police and to prosecutors. But that is not exceptional. We also know

from other subjects of Elder Abuse that the judicial system just see the tip of the iceberg.

However, financial abuse is a serious crime and elderly are attractive targets for this criminal offense: Older persons often own money and other valuables including property. They often receive their pension at the same time. In view of that perpetrators can follow predictable patterns and know exactly when to contact the elderly or when the elderly probably will go to the bank. Older persons often are dependent on the help of others including the perpetrator, who in that case has easy access to the victim and his/her home and might misuse his influence on the victim. The victims themselves may not be able to report exploitation because of their frailty, physical or mental disability, or their impairment. They may be ashamed to report - because the perpetrator is a close family member. They may be afraid of the consequences of a report to the judicial system - because of their dependency on the abuser and their fear that they might have to move from their home to a nursing home. They also may not be familiar with financial matters. And in some cases they may not even notice the abuse.

Anyway, in case of a criminal report police and prosecution face problems to collect the necessary evidence.

From a prosecutors view we can classify all the different types of financial abuse in four locations with specific means to a potential investigation and prosecution. The question marks show clearly the difficulties coming up for policemen and prosecutors. And they also reveal that the more vulnerable the victim is the more investigations are likely to be not successful.

1. CRIMES BEING COMMITTED IN PUBLIC BY AN UNACQUAINTED PERPETRATOR

- The perpetrator and the victim are unacquainted
- The location for the crime is well selected:
 - Cemetery, entry door
 - A lonely spot, no other persons are around, the attention of the victim is drawn off
- The victim is quite a lusty older person, because he/she can still go out
- Probably the victim is a capable witness (because of the quite good

health conditions)

- Probably the victim is willing to testify because the perpetrator does not belong to his/her inner circle
- Other witnesses might be available (public location)
- Reports to the authorities are most likely
- Police is interested in investigations
 - Often serious crime
 - Public attention
- Chances for a sentence rather likely
 - If the perpetrator can be identified.

Examples:

- Robbery
- Handbag snatching, sometimes with fatal outcome for the victim

2. CRIMES BEING COMMITTED AT THE VICTIM'S HOME BY AN UNACQUAINTED PERPETRATOR

- The perpetrator and the victim are unacquainted
- The location for the crime is well selected:
 - Perpetrators drive through neighborhoods to find persons, who are alone and isolated
 - Perpetrators are checking newspapers for death announcements (to find alone living persons, widows/widowers)
- Perpetrators are checking names in telephone books (to find older persons with old fashioned names)
- The victim can still be quite lusty, but can also be rather fragile
- The capacity of being a qualified witness depends on the health status
- Probably the victim is willing to testify because the perpetrator does not belong to his/her inner circle

- Other witnesses are most likely not available
- Reports to the authorities are most likely
- Police is interested in investigations
 - Often serious crime
 - Perpetrators might be criminal gangs
- Chances for a sentence rather likely
 - If the perpetrator can be identified
 - If the witness is capable to testify.

Examples:

- Robbing/stealing money and possession
- Investment fraud
- Announcement of a prize that the elderly person has won but must pay money to claim
- Telemarking scams (perpetrators call victims and use deception, scare tactics, or exaggerated claims to get them to send money)

3. CRIMES BEING COMMITTED AT THE HOME OF THE VICTIM BY AN ACQUAINTED PERPETRATOR

- The perpetrator and the victim are acquainted (family member, care giver, neighbor, custodian etc.)
- The location for the crime is well selected (loneliness, help, dependency etc. of the victim)
- The victim can still be quite lusty, but can also be rather fragile
- The capacity of being a qualified witness depends on the health status
- The victim is probably not willing to testify because the perpetrator belongs to his/her inner circle and the elderly does not want to put their relationship at risk
- Other witnesses are most likely not available

- Reports to the authorities are most unlikely because of the relationship (and/or the health status)
- Police is probably not interested in investigations (family matters, behind closed doors)
- Chances for a sentence are rather unlikely.

Examples:

- Misuse personal checks, credit cards, or accounts of the elder person
- Steal cash, income checks, or household goods
- Using the older person's property or possessions without permission
- Getting, deceiving an older person to sign a deed, will, or power of attorney through deception, coercion, or undue influence
- Promising lifelong care in exchange for money or property and not following through on the promise

4. CRIMES BEING COMMITTED IN DOMESTIC OR INSTITUTIONAL CARE SITUATIONS OF THE VICTIM BY AN ACQUAINTED PERPETRATOR)

- The perpetrator and the victim are acquainted (family member, neighbors, friends, doctors, nurses, hospital personnel, other professional care providers etc.)
- The location for the crime is well selected (loneliness, help, dependency etc. of the victim)
- The victim is very fragile
- The capacity of being a qualified witness depends on the health status, probably more likely of facing mental problems (age)
- The victim is probably not willing to testify because the perpetrator belongs to his/her inner circle and the elderly does not want to put their relationship, at risk/ fears consequences/bad treatment
- Other witnesses are most likely not available
- Reports to the authorities are most unlikely because of the relationship and the health status

- Police is probably not interested in investigations (behind closed doors)
- Chances for a sentence are rather unlikely.

Examples:

- Not providing health care, but charging for it
- Overcharging or double-billing for medical care or services
- Getting kickbacks for referrals to other providers or for prescribing certain drugs
- Recommending fraudulent remedies for illnesses or other medical conditions
- Over medicating or under medicating

In most of the cases the elder victim is supposed to be the only witness, the only evidence available for the investigators. In terms of the criminal conviction of the perpetrator investigation and trials can only be successful if the witness can satisfactorily show what crime happened, can provide prosecutors and judges with the necessary evidence and state plausibly the circumstances of the criminal act. But the increase of age often goes along with the decrease of mental capacity, with Dementia, Alzheimer's etc..

Can a person suffering from these medical conditions be a good attester at all?

Police, prosecutors and judges do not have enough knowledge of aged people in general; nor do they have enough knowledge about the above mentioned diseases and their influence on the capability of a witness.

The human population is getting older and older. Consequently the judicial system will face more high aged perpetrators and victims and will have to deal with this issue as decades ago in the context of sexual abuse with the reliability of the statements given by children; in which respect the judicial system can nowadays draw upon many years of experience.

Judit Kozma [HU]:

“Self neglect versus Diogenes syndrome of hoarding”



For the social workers who work with elderly, this picture is familiar. The heaped junk: dirty dishes, dolls, some tools which are maybe usable for painting, jewellery, fancy small things. This lady is maybe an artist. We can't help admiring the picturesque view of her, smiling gracefully and the colourful things crowd around.

For many years I was a consultant supervisor of several social services' teams mainly social workers who worked with elderly and handicapped people. When I prepared for this lecture a lot of stories popped into my mind, all of them heartbreaking. I remember that poor old man who lost his legs because of peripheral vascular disease related to hypertension and diabetes. He had to stay in the bed since years when our colleagues were called by his neighbours to do something because they had not seen his wife since a couple of days and nobody answered to their ringing. When they enter his home with the help of the police they had to run the blockade because his home was full of radios and radio parts as he was a dedicated ham, tools, dirty dishes, remaining of food, dirty clods, newspapers, wheelchair out of reach, bucket full of urine and excrement, awful smell. His wife was in the bed besides him, she died several days before. He was half dead too without food, water and medication.

He did not want to go to the elderly home but there was no other solution. It is very easy to understand his behaviour of hoarding. He could not move and he wanted everything at hand which would be needed so that he could keep contact with his friends in the distant parts of the world with radio.

So what the professional literature says about that situation? One term for that is:

Serious self-neglect

Serious self-neglect is characterized as behaviours of an elderly person that threaten his/her own health or safety.

1.USUAL SYMPTOMS:

1.Refusal or failure to meet basic needs (food, water, clothing, shelter, and safety)

2.Refusal or failure to maintain personal hygiene

3.Misuse of medications or mixing medication with alcohol

2.OFTEN SERIOUS SELF-NEGLECT GOES TOGETHER WITH HOARDING WORTHLESS ITEMS EVEN THOUGH THEY APPEAR TO OTHERS TO HAVE NO VALUE OR EVEN AS RUBBISH.

The other term in Psychiatric textbooks:

Diogenes Syndrome.

3. adoption of a reclusive and squalid lifestyle

4. hostile rejection of the outside community

5. sufferers often live in restricted spaces

6. hoard what others see as rubbish

7. wear peculiar clothes

8. usually do not welcome outside intervention

9. most of the sufferers have intelligence above the average

5 people in 10000 are affected.

As the surveys show, these problems account for the majority of cases in which the adult protective services are called to intervene.

What do these cases mean for the care workers?

Multiproblem cases

1.Physical illnesses which sometimes are caused or worsened by the self-neglecting behaviour

2.Psychiatric symptoms which can be caused by psychosis or dementia or isolation or sensory deficit or social breakdown (losses, drop in social status, isolation, losing social competences, low self-esteem, failing in coping with decreased capacities, etc.) or some composition of these

3.Economic stresses: lack of resources needed for self-maintenance

4.Hostile neighbours: expelling, physical, verbal, financial abuse, exploitation

5.Problems of caregivers or other relatives

When I recall these symptoms, a lot of cases occur to me. I remember the old lady, a layer. She lived alone in a block of flats and the care service was asked to intervene by her friend. Her neighbours regularly abused her, tried to expel her so that they could occupy her flat. It took several weeks until the care workers could obtain her trust and get into her home. The manager of the home care service said: "We went along every day and knocked. What other we could do with that very clever and stubborn old lady?" The social workers in this case gained a victory in the battle with the neighbours. In a lot of cases the neighbours succeed and the undesirable old, dirty, smelly neighbour is forced to go to the streets as a homeless.

Dilemmas of practitioners

10.Wellbeing vs. freedom dilemma

It is written in the ethics of social work that we have to respect the free choice of the service user. The old person even can decide not to use the service. But sometimes when we respect the independence of the old person who seriously neglects herself/himself, we sentence ourselves to be witnesses of slow suicide. The other solution is the guardianship. But how we can be sure that we not counter the deliberate will of an adult? It is very frequent that the relatives, neighbours and even the care workers relate to the old people as if they went back to child

age. But this is not fair. One of our client said once upon a time that “I am only old but not stupid!” We have to ask ourselves several times, whether we like to be handled in the same manner as we do to our old clients. But in several cases we have to protect the carer of the old client as well. This is the well-known loyalty dilemma. It is also not fair to force the carer to sacrifice herself because her mother's or father's senile break down ruins her life, drain out all of her energy.

The other situation when the old person living in elderly home and her/his squalid lifestyle pose a risk for the other inmates. As my colleagues told me this is the situation when the leader of the elderly home should instructs the chamber-maid to steal the old person's treasures.

11.Clients must consent to services

12.Caseworker must be resourceful

This is the other serious problem. Care workers usually overburdened with a lot of cases, have a quite big service area and have to travel a lot to her clients. Simply she has no enough time to make a thorough assessment and to negotiate the service details with the client. Although the care worker usually knows well what the old person needs for the enough safe environment but the poor old client has no money for the aids and the care worker also has no budget for change the risky elements of the environment. The other resource of the worker is her/his knowledge. Well, sometimes this is missing too. The average home care worker is not skilled, middle-aged, low-paid woman.

13.The process of improvement of the situation may take a lot of time

14.These cases are very stressful for the practitioners

Being middle-aged ladies just like the care workers we always think about what we will look like when we will be old. So these cases are very stressful. The other sources of stress were mentioned: the loyalty dilemma, the lack of resources and skills, the big caseload, the low salary and prestige, etc. And the supervision is missing too from the majority of the services. Anyway we have to admit that even the best supervision cannot change the main stressors.

SO AT THE END OF MY LECTURE HERE ARE SOME PRINCIPLES FOR THE INTERVENTION

15.We have to take into consideration the complex factors behind the case

16.We have to respect the free choice of the elderly but recognize when

the situation becomes too threatening for the client or for the others

17.We have to maintain maximum flexibility

18.And we have to support the social network which can be mobilized in the interest of the old people at risk

As far as possible!

Helene Hamlin [USA]

“Loneliness as a form of neglect. How to identify loneliness”

My thanks to the organizers of this important meeting for the opportunity to join you in this panel. My colleagues have discussed abuse and the elderly. I was asked to discuss loneliness in the context of the care and protection of older people and how the consequence of loneliness can lead to neglect and thence to abuse.

To me, loneliness actually refers to social isolation, and includes issues of health and mental health, poverty, family interactions and society's view of older persons.

I approach this complicated and moving topic from the perspective of a social worker, someone who has been deeply involved in the day-to-day lives of older persons: people who live in the depths of loneliness, who have become increasingly isolated and despairing as they grow more and more frail; people who have more and more difficulty handling the activities of daily living and accessing needed services. These services include safe housing and physical and mental health care. I have worked in situations where even when services did exist, they were inadequate – due to lack of planning, lack of resources and because the numbers requiring intervention had become overwhelming. The majority of people in need of intervention – who have become isolated and lonely, are women, although there is a growing population of men. Men are living longer than in the past. When they do not make new connections, such as remarriage, they seem unable to cope with their changed status. More research is needed regarding older men.

Eric Erickson, the noted psychoanalyst, remarked -- and I am paraphrasing—that in earlier times, when adults lived to what we called

venerable ages -- 70's, 80's, even 90's, they were regarded as "elders", the repositories of history, experience, wisdom, cultural heritage and traditions. And they were honored and treasured. As more people live longer, into their higher years, they are no longer seen as elders -- they are elderly. (Think of the rapid growth in the numbers of centenarians.) As the world has experienced the tsunami of an ageing population, older persons have become commonplace -- no longer treasured and sought after, but more often seen as annoyances, burdens, 'problem people' who need too much care and use up limited resources. And the old persons are angry, despairing, finding it difficult to cope with increasing frailty, increasing disappointment in their situations, leading to increasing isolation and even to suicide. This latter is a real problem among older men.

Factors to be considered for both men and women are feelings of being unfulfilled in their lives that many people harbor as they age; how being poor, living in poverty, hurts physical health and psychological development; how lack of education and/or employment and advancement can hold them back; how lack of respect and dignity are all negatives in these lives. The Human Rights of Older People are not respected as they must be. These elements are important to consider as we think about the care and needs of our older citizens. We have to think about the role of families in the lives of older persons -- who are they, where are they, are they part of an older person's life both in fact and in connection? Has migration, civil strife, disease, fractured the family? And what role does poverty play in loneliness and social isolation and how this may can be relieved.

I will talk about what I see that constitutes loneliness, and why I believe this condition may be considered abusive. And then I want to share information about social services that are successfully enabling isolated, lonely older persons to rejoin society, to feel better about themselves and their worlds, to even feel needed, useful and valuable to others as resources, even though they may be in dependent circumstances and frail health.

What is meant by loneliness, by social isolation. It is when a person is shut off -- or shuts himself or herself off -- away from family, neighborhood and community networks. It is caused by lack of meaningful social relationships, mental illness, personal disorder, dysfunctional family systems. The effect on individuals results in that person being ignored,

neglected, self-neglecting, deepening loneliness, being shunned by a personal network, and subject to abuse by others.

Loneliness takes many forms and can lead to abuses such as being ignored by meaningful others, can include stealing funds, failure of others to participate even minimally in the older person's life, physical abuse when contact is made, failing to take action when illness appears, withholding medications. In my experience, there have been many times when I have been called by the local hospital where an older relative has been dropped off, usually in the middle of the night and just left! Left to be cared for by the hospital, then Adult Protective Services, and in some cases, left to die. In other words, dumped - like an unwanted parcel or a leftover.

We have to examine the concept of loneliness: There is what we can term "pathological loneliness"; this can be a result of true mental illness. There is another pathology, just as real, which comes about when individuals grow up not feeling truly connected to their nuclear families, not felt nurtured, cared for, loved, even when living with family. These individuals may never have developed the ability to have positive, reinforcing relationships. I have had some people tell me they have always felt "left out of life" --and they then become disengaged. Some have married and had families, but repeat the patterns of uncaring that they experienced themselves. This feeling of disengagement at the most elementary level leaves people on the outside. Such people are lonely! You can see them in your senior centers or on park benches, not participating but sitting on the side, eating alone, rarely responding to a greeting. Or they become recluses and remain behind their doors even in busy urban areas.

Reaching such people requires great patience, time and skill in getting to know them so they can trust in a friendly greeting that may lead to a conversation, that may lead to some possibility of engagement besides coming to the center to eat a meal. Little by little some of these lone persons can become part of a group. Sometimes all it takes is finding out what interests the person has or had, and starting to make a connection with an activity.

There is loneliness due to the losses one experiences as age accumulates: widowhood; development of chronic health problems; loss of functions such as after a stroke or a fall ; loss of hearing; loss of sight; unwillingness to use ambulatory assists; exacerbation of early physical

problems; increasing anger at one's appearance. Persons with disabilities from an early age may have adjusted well early on, but with ageing, have deteriorated and then become withdrawn. These persons may isolate themselves more and more. We need to find them and attempt to re-motivate them. I have found that many people who once did volunteer work can be helped to re-enter, if their current conditions permit and interests can be aroused. An example from my practice was finding alert nursing home residents who became surrogate grandparents for children who came home to empty houses because the parents were working. We called these children "latchkey kids". They could call the older persons and talk to them about home work and other interests. Both generations were connected to each other. I must add that this is a very difficult program to institute and maintain, but the effort is worth it.

I said earlier that we need to consider the role of poverty in issues of loneliness and social isolation. Many of today's older women may not have had paid employment or if they did, the work did not allow for savings – in fact, many worked to send money to other family members, such as the remittances that continue to this day, or shared with those they lived with. In addition, when there are pension schemes, in many countries, they are marginal. In today's financial climate, even so-called adequate pensions have become marginal and meeting one's daily living needs are becoming more and more difficult, adding stress and strain to the individual and to family relationships.

Employment for women, and for many men, particularly for those with limited education was – and still is -- in the service categories. This is work that is necessary for society, such as housekeeper, maid, waiter or waitress, cashier, low paying construction work, caring for other people's children, becoming health care workers, such as aides in nursing homes or in home care programs. These latter jobs pay little and are still not geared to career ladders that could eventually advance workers to higher levels and better pay. Many of the poor women who have been left behind when families move on – as in some countries –who become isolated, discouraged, perhaps disparaged by their families, despite what we call "family networks", may end up with emotional disturbance. They then become isolated, disconnected and lonely, which is deepened as well as by increasing frailty brought on by illness and the development of chronic conditions.

Research has shown that maintenance of connections is vital to health in older age. The Madrid International Plan of Action on Ageing, the great document of the 2002 Second World Assembly on Ageing (MI-PAA) talks of "health and well being into older ages" and refers to not only the physical but to mental and emotional well-being. This is not the place to discuss the mind-body connections in health, but it is well-known that there are complex interactions of the mental, emotional and physical aspects of being human beings.

Other factors that increase loneliness and social isolation stem from some traditions in societies that practice them. For example, in some cultures, when a woman is widowed, her house and/or the family business does not belong to her but is given to the oldest son. These traditions may also apply to elderly men as well in certain circumstances.

And persons do not have to be poor to be isolated,

Frequently we hear stories about older persons living in isolation who are not poor, but who become victims of financial and other abuse when perceived as frail or demented. Even when surrounded by family, as in the current case of the very rich Mrs. Astor who was being looked after by her son. It has become a publicized case of financial abuse with her elderly son accused by his son, to have forged his demented mother's signature on documents that changed her intentions regarding her estate. It is also alleged that she may have been medically neglected as well.

Many older persons find themselves as the last ones in their families to have survived as long as they have – due to illnesses, to civil strife, to migration. For example, the grandchildren they may have brought up also leave, thus increasing isolation.

There are communities that end up being populated mainly by elderly. Being left on their own is surely devastating to older persons, (although these days, there are more and more deliberately organized retirement communities in developed countries).

Let me turn now to the kinds of interventions and programs which I know about that have been successful in reaching out to the lonely, the socially isolated, frail and homebound elderly whose ranks are growing so rapidly in our various countries, in urban and rural area.

What can we offer to this group of our older citizens who we identify as lonely and isolated, having few family and friends around them; having very few or no persons to take an interest in them? Many of this group have pulled away and no longer feel any attachment to society.

There are services and programs that can be and have been developed and promoted to reach them, to find ways and means to re-connect them or prevent others from being neglected and abused and to keep these individuals in the loop of life.

Programs such as “Meals on Wheels” or “Meals on Heels”, depending on how these are delivered. Someone is bringing those packages of food to the older person. These deliveries are accompanied by some social interaction – even asking “how are you today” can be meaningful and shed light on otherwise hidden needs. Delivery persons can be trained and encouraged to express the simplest of greetings and over time can gauge a person’s behavior, notice changes and bring such information back to the source of the food for follow up.

In a program that was attempted some years ago in New York City by our Department for the Ageing, postmen were asked to notice if mail boxes were being emptied or noticed that the mail was not being picked up over time. The Department was notified and would use local services, i.e., social service agencies, senior centers, visiting nurses, to make contact. In some programs, in arranging for the home delivered meals, older people themselves, volunteering at the source for the meals, make telephone calls to the homebound to ask what menu items they would like, and have a conversation about that. This is a connection. Daily telephone calls from senior volunteers in a center telephone reassurance program, is another connection. Yet another service offered is using young volunteers, usually high school and college students, to escort the frail to medical appointments, go shopping with them, or go shopping for them. Once a year, one program arranges for the homebound to visit the graves of their loved ones.

I cannot leave this topic without noting that none of this is easily accomplished. There are many difficult aspects of developing and carrying out these program – and not the least of the concerns is resources, to support the recruitment, training and supervision of volunteers. The issue of transportation for older persons, whether homebound or ambulatory, is critical in order for elderly to keep to their vital errands, such as medical appointments.

I point out that if we cannot get persons with or without resources or connections of their own to their vitally needed medical services, we are not attending to their health needs –or other social needs-- and in this we are also violating a basic human right. Policy makers need to be aware of this problem, which I know is universal – it is much the same problem in New York City as it is in Johannesburg, South Africa. There is a role for governmental planning and policy here. It is not an easy task, it requires financial resources and people power to effect changes. We who are serving older people must make strong efforts to fulfill our service missions.

We must also find ways to empower and enable citizens to work together to affect the atmosphere of change and betterment with the governing bodies. As the Madrid Plan tells us, we should utilize the bottom up approach, that is, at the grass roots: in the centers, in the clinics, in the neighborhoods and then find opportunities and ways to influence the governing bodies. We can bring knowledge and experience to the policy people at the higher levels. And we must alert legislators and those around them to the social and health complexities inherent in addressing the issues of social isolation. We must do this if we are to truly build a society that is responsive and benefits all ages. The MIPAA and the Berlin RIS are blueprints to show the way. Are we educating the constituencies to make this more of a reality?

I want to share information about yet another program to combat social isolation and loneliness that utilizes the conference telephone, beyond telephone reassurance. DOROT, a social service organization in New York City has developed a program called “University Without Walls” – a successful effort to bring lifelong learning by telephone to people in their own homes by offering classes in almost every conceivable subject, taught by well qualified instructors, usually volunteers. The program has grown remarkably over the past 15 years, connecting isolated and frail homebound. The connections made over the telephone are meaningful and dynamic, have created friendships, have awakened interests in subjects of all kinds, such art (taught by museum personnel), opera and other music, current events, investing, languages, folk songs, reminiscence, writing. The list is long and indicative of the lively minds pursuing these interests.

And for those capable and able, the computer has also demonstrated the many connectivity aspects that benefit today’s older persons.

We are already aware that loneliness and isolation can lead to depression and other emotional problems, perhaps exacerbating already existing conditions. To limit if not prevent these effects, telephone contact is vital. The University Without Walls program has had a remarkable effect on the frail, isolated homebound. It has changed many lives over the years by reducing isolation, by encouraging connections among the participants. There is now a Russian UWW . People connect over a wide area. I have friend who teaches finances and investing from his home in Switzerland to his class in the New York area. Anything is possible with the telephone and soon probably with the internet – when today's baby boomers become older and frailer. This program has also arranged for out of home opportunities as well – such as concerts at the site of the organization, planned trips to museums for those in wheelchairs and walkers. These participants are no longer isolated despite their frailties and homebound status.

The last program I will share with you is the concept of Friendly Visiting to the isolated homebound. Again it is a DOROT program. This organization was begun about 35 years ago by university students in a crowded area of New York City when these kids noticed and then found many lonely, frail, homebound elderly. What began as a tiny effort to visit and interact with homebound elderly has grown into a large multi-service social agency. Friendly Visiting remains at the core, now greatly enlarged. Because of the rigorous way in which the program has been structured, there are now hundreds of volunteer Friendly Visitors, including whole families, who make the commitment to weekly visits for a year. Visitors include older persons, both men and women, teen age youths, young persons from all walks of life (indeed, several big corporations and law firms have developed friendly visiting volunteers from among their employees).The volunteers are screened in depth, as are the older persons who request this service. Social Work staff make and supervise the matches and train the volunteers to be their eyes and ears. Volunteers are brought together for group meetings to exchange experiences and on-going training.

This program is a very individualized combination of people who had never met but who are now in this relationship. I cannot tell you how many matches have become real relationships and substitute families for the older people. I have heard many stories of deep friendships that developed over years of contact. The volunteers say that they have gained as much, even more than the older friend. Musicians bring their instru-

ment to the visits; an older man teaches a young boy to play chess; a former professor of mathematics tutors a high school teen on algebra; a Holocaust survivor talks about the history of that era; communities of interest are discovered.

I have brought my friend Jan Lorman a gift from DOROT: a kit about how to develop and carry out this program. It includes manuals for professionals, volunteers of all ages, including for families visiting together, for teens and even children joining their parents in visits.

In thinking about combating loneliness and social isolation, I have come to regard Friendly Visiting as caregiving. This program augments the more traditional, informal caregiving by an immediate or extended family– and the formal type of home care by an agency such as the visiting nurse. In the situation of the isolated lonely, older person, the Friendly Visitor becomes the family, the vital connection to the outside world.

DOROT is also in the midst of developing an International Friendly Visiting Association, which can be found, as all of the programs, at the website: www.dorotusa.org

The key to keeping loneliness at bay is connection. To help keep abuse and abusers away, we must pursue keeping people connected. The programs I have described are vital and effective in doing that. We know these programs have made real differences in the lives of the older people: they tell us so – their faraway families tell us so – and the level of connection and communication in this multigenerational effort tells us so.

Again, I thank the organizers of this conference for the opportunity to bring this important topic to the forefront of our thinking and to share program possibilities to deal with loneliness and social isolation.

Workshop Report

DEVELOPING AN EXPLANATION OF MISTREATMENT
by SIMON BIGGS

Responsibility for other

Research / policy definition: single or repeated act or lack of action in relationship where is expectation of trustcause harm or distress to older person

Expectation of trust / partner, spouse, family, friend, professional and even neighbours and acquaintances

Person mistreat would recognize abuse or mistreatment ... according to definition the broadness show wider public is involved in abuse act.

- From research- even what could be abuse/neglect

Public opinion from eurobarometer shows huge difference reality and suggestions / people believe in 14% physical abuse

Trajectories of prevalence show difference in occurring EAN.

Spread definition any harm done to older person that undermines person's physical emotional, spiritual or wellbeing.

NEED FOR CLEAR BOUNDARIES THAT CAN IDENTIFY EAN / TRUST, FREQUENCY MUST BE DEFINED.

- Vary the definition / vary the prevalence
- Specific dynamics for specific forms
- Little evidence of multiple clusters

VIOLENCE VERSUS ABUSE

by ZVI EISIKOWITZ

Abuse as commission / neglect as omission Reay and Browne 2001 ... researchers constructions are important

ABUSE AS ACT:

Mistreatment as intentional action by trusting relationship or b) failure of caregiver

Example: Elder abuse impact on old women, adult daughter, social worker as actor [everybody version ... who is responsible when they stay in relationship of abuse? Daughter who came and help the practical solution, mother who don't want to do anything and is put to carehome against her will or social worker who should intervene even known it is problematic family and husband refuse anybody to come to home ...]

Social content is constructed by narratives ... in her community abuse was taken for granted, what make sense for them / what is abuse...

FINANCIAL ABUSE, PRACTICAL EXAMPLES: THE VIEW OF A PROSECUTOR

by GABRIELE VALENTICH

CRIMES ARE INFLUENCED by... location [loneliness, dependence, any kind of evidence afterwards], health status is always good chosen by perpetrators...

capability as witness[to know a bit more about older people, report to authorities is a problem ... it depends on health status of victim

Telemarketing scams... very important crime in GE [grandmother guess who is calling, come with me to bank and get some money....]

Acquainted makes things difficult because of relationship and trying to preserve them ... it comes to prosecution really few times

SELF NEGLIGENCE VERSUS DIOGENES SYNDROME OF HOARDING

by JUDIT KOZMA

Social worker for elder people experience with problem – hardbreaking stories during those practical experiences with hygiene and taking care of oneself

Behavior – couldn't walk and couldn't receive anything from outside, so he keeps it with him

- It could be seen as serious self neglect – hoarding worthless items even they appear to others to have no value... called Diogenes Syndrome. Usually 5 people in 10 000 are affected.
- Multiproblem case – physical illness, psychiatric symptoms, isolations, social breakdown, economic stresses, hostile neighbours, problems of/ with caregivers or relatives
- Dilemmas of practitioners: wellbeing versus freedom
 - Consent to services of clients
 - Cases very stressful for practitioners
 - Process take a lot of time
- Intervention – complex factors behind
 - Respect free choice, but recognizing the threatening situation
 - Maintaining maximum flexibility
 - Support social network which can mobilize

DOES OPPORTUNITY MAKE THE ABUSER? STRAIN AND OPPORTUNITY FACTORS IN ELDER ABUSE

by THOMAS GORGEN

Criminological theories:

STRAIN THEORIES / DEVIANCE

Control theories / not deviance but conformity needs [opportunity makes abuser]

Germany / criminal victimization is less in old age also for self-report decline

Older people have more precautions against victimization, reducing their risk

According to types of crime ... strain perspective in most cases is inappropriate / because of the taking care of who is victim [fragile, small, older women]

MISTREATMENT / DOMESTIC CARE FROM CRIMINOLOGICAL PERSPECTIVE ... CAREGIVING IS SUPPORT / CARE GIVING OFFER OPPORTUNITY FOR ABUSE ... survey in home/care nurses shows how it works... risk-factors: assaults by care recipients, regularly care for high number of people, stress

Risk factors for abuse in domestic system:

Low quality of relationship, stress, financial motivation, poverty, bad physical, mental health and so on

CONCLUSIONS: both strain and opportunity driven [mainly financially could be seen as opportunity]

Lack of formal and informal social control make the perfect crime scene.

Elder abuse prevention needs to keep both the strain and the opportunity pathways in mind

LONELINESS AS A FORM OF NEGLECT. HOW TO IDENTIFY LONELINESS

by HELEN HAMLIN

Loneliness / could be abuse because they are frail, alone

They are some people who come to ask for help but also we have to go out and find those people

They don't go out, they become to neglect themselves, don't go shopping

Lonely, frail need to be reached out ... people sitting on benches, because they are not so lonely when on public area

DOROT program ... to talk to lonely people by students organization, informal visiting them, utilizing volunteers ... it prevents abuse, because there are connections with others, they are supervised, recruiting different people who are carefully trained to visit elder friends

.. have connection with outside world

FRIENDLY VISITED KID volunteers, by telephone connection.

www.dorotusa.org

...we are not in time to ask the question. Any question wasn't risen

2. WORKSHOP

2.1. WORKSHOP:

NATURE OF HEALTH COMPLAINTS AND DISABILITY IN THE ELDERLY

Key question: Consensus on minimum European standards in the care of geriatric patients/clients in institutional care: hope or fiction?

CHAIRPERSON: Jan Jařab [CZ]

REPORTER: řTEFAN Krajćík [SK]

ASSISTANT: Peter Tropko [SK]

Paul Knight [UK]

“GERIATRIC MEDICINE AND THE END OF THE DISEASE ERA”

Medicine of the 20th century has relied on gaining knowledge about

the patho-physiological mechanisms of disease to attempt to effect a cure through short episodes of care. It has become more and more apparent that in a Europe where the population is ageing, increasing organ subspecialisation by physicians will not necessarily adequately meet the needs of older people.

Older people frequently have multiple morbidity and move between states of normal function, disability and frailty presenting with geriatric syndromes characterised by common risk factors and features. These syndromes frequently do not have singleton causes making them unsuitable for care by organ specialists alone. Geriatric Medicine Specialists concentrate on treating individuals rather than disease states and there is good evidence to suggest that their team approach improves health outcomes for older people.

Unfortunately, geriatric medicine is still poorly developed in Europe and the European Geriatric Medicine Society serves to promote its development across the continent.

Iva Holmerová [CZ]

“CONSENSUS ON MINIMUM EUROPEAN STANDARDS OF CARE OF GERIATRIC PATIENTS/CLIENTS IN INSTITUTIONAL CARE: HOPE OR FICTION?”

The health and social care systems differ in individual EU countries. The long-term health and social care is provided on a satisfactory level in some countries, and it meets the citizens' needs. In other countries, it still presents an unsolved problem. It is taken as part of life of Europeans that their countries provide a variety of services including the services for the older persons, and will be taken as such for a long time to come. Mobility, however, is an important factor as well, and not only in connection with the young people. It is also us, the ageing Europeans, who grew accustomed to consider mobility as an important part of our lives. The great variety of services may pose a certain problem, however. As for me personally, I don't think that it will be possible to determine in the near future the unified European standard of services that are provided by certain institutions. I do think, however, that the professionals and potential clients of these services should develop a very intensive discussion about the principles behind these services and about

the expectations of the consumers and this not only in relation to the services provided by the institutions, but, also, more generally, in relation to the individual great health challenges and geriatric syndromes. I think that some steps in the right direction were taken in for example the Alzheimer disease issue on part of the Alzheimer Europe association and the French EU Presidency. I would be grateful if our conference pointed out other important directions in which the “European principles” or “European expectations” can be formulated.

Ingrid Söderback [SE]

“PROCESS OF HOSPITAL DISCHARGING FRAIL GERIATRIC PATIENTS”

This presentation concerns geriatric patients' caring and rehabilitative process that occurs after an acute admission to hospital, when medical treatments are fulfilled, and the patients are in the transferring phase from the hospital to his / her home. These geriatric patients are in Sweden over 75 years old, however often younger in the East European countries (Aldskogius, et.al., 2001). They are characterized by having functional limitations; having difficulty in performing activities of daily living (ADL) (Neufeld et al., 2004; Renforth et al., 2004); and having multiple diagnoses, e.g., fractures, heart and cancer diseases (Swedish National Board of Health and Welfare, 2009).

Workshop Report

PAUL KNIGHT (UK): GERIATRIC MEDICINE AND THE END OF THE DISEASE ERA

- Co-morbidity and multi-morbidity
- The emergence of geriatric syndromes
- The concept of frailty

Features of medical complaints in old age are very different from those in young and middle age.

Geriatric syndrome – multifactor health condition that occurs when the accumulated effects of impairments in multiple systems render an older person vulnerable to situational challenges.

Clinical thinking of geriatricians is different very often. A disease causes multiply problems in middle age. In old age one complaint is caused by more diseases and it is difficult to treat these complaints.

Specialists in geriatric medicine often concentrate on treating individuals than disease states. If a team approach is applied, the outcomes of treatment are significantly better.

Ingrid Söderback (SE):

“PROCESS OF HOSPITAL DISCHARGING FRAIL GERIATRIC PATIENTS”

Good care for the elderly needs to make good connection between institutional and outpatient care because elderly patients are most vulnerable to two to three weeks after discharge. Discharge has to be done in organized way, needing a cooperation of more specialists (doctors, rehab workers, occupational therapists etc.) With this approach we can see improvements in outcome of care.

Iva Holmerová (CZ):

CONSENSUS ON MINIMUM EUROPEAN STANDARDS OF CARE OF GERIATRIC PATIENTS/CLIENTS IN INSTITUTIONAL CARE: HOPE OR FICTION?

Care for elderly people can be improved by using standards but this approach has many problems and pitfalls. The problem is setting of level, using a high level can be unrealistic and using too low level is meaningless. There are big differences between various countries of the EU and it is impossible to set standards for all member states.

Recommendations:

1. Developing geriatric medicine a improving access to geriatric services
2. Implementing geriatric assessment and planning of discharge
3. Discussion on standards of care

2.2. WORKSHOP :

DIGNITY AND ELDER ABUSE AND NEGLECT IN HOSPITAL CARE AND IN LTC FACILITIES

Key question: European Standards on restraint using in LTC

CHAIRPERSON: Ariela Lowenstein [IL]

REPORTER: Pavel Weber [CZ]

ASSISTANT: Jaroslava Hasmanová Marhánková [CZ]

Sirkka-Liisa Kivelä [FI]

“Chemical restraints in the care of the aged”

Ladies and gentlemen, my topic is chemical restraining as a form of elder abuse. I shall describe definitions of chemical restraints and continue with the prevalence figures and reasons for the use of chemical restraints. In addition, I shall talk about consequences of their use. Lastly, I shall make some proposals.

My presentation is based on a systematic collection of data about studies concerning chemical restraints in the care of the aged. A year ago a literature search was performed in the PubMed database by using the keywords “chemical restraints, psychotropic drugs, and aged” with their synonyms and equivalent MeSH terms. The reference lists of the articles identified in this search were used to complete the search. There was no restriction on the language. The articles were published between the years from 1977 to 2008.

The first selection of articles was based on the titles and abstracts of the publications. The abstracts were read. The further collection of articles was based on the contents of the abstracts. Literature reviews and original studies about chemical or pharmacological restraints in the aged were collected and read in the second phase. In addition, original studies about the use of psychotropic drugs produced by the search were collected and read. The form of living of aged persons was not restricted.

The search from the database produced 128 articles. According to their abstracts, 20 articles were potentially eligible for inclusion. Their reference lists produced 42 additional articles. After reading all these 63 articles, 31 were found to consider definitions or prevalence of the use of

chemical restraints and reasons for use of chemical restraints in the care of the aged. These 31 articles were accepted to this literature review.

DEFINITIONS OF CHEMICAL RESTRAINTS

Chemical restraints are commonly defined as drugs administered for the purposes of discipline or convenience or for the purpose to limit the physical movement of the resident and not required to treat the resident's medical condition. Some researchers use the term "pharmacological restraints" as a synonym for the term "chemical restraints". In some determinations, the drugs used in chemical restraining were specified, usually as psychotropic drugs. The type of use was specified in some definitions by the terms regular, continuing or persistent use. An additional remark about missing of full consent of the patient for the use was added in some definitions.

HOW COMMON IS THE USE OF CHEMICAL RESTRAINTS IN THE CARE OF THE AGED?

Only 4 studies about the prevalence of use of chemical restraints by using the definition chemical restraining as the aim of the study were found. All these studies were performed in institutions. Two studies were performed in acute hospitals in Australia or Canada, one study was performed in traditional nursing homes and homes for the demented in the U.S.A. One study was made in long-term institutions in China. No studies with a specific focus on chemical or pharmacological restraints performed in Europe were found.

Medical records, interviews of the personnel in the institutions and observations made by the research team were used in data collection for these studies.

The results show that the use of chemical restraints is quite rare in acute hospitals. From 2 to 6 percent of aged patients had been pharmacologically restrained. However, the use of chemical restraints is very common in nursing homes, in homes for the demented and in other kinds of long-term institutions. Nearly a half of the residents had been chemically restrained in these kinds of long-term institutions.

There are other kinds of studies, too, where the possible use of psychotropic drugs in pharmacological restraining has been discussed. Our search produced seven studies about the prevalence of the use of psychotropic drugs among the aged, in which the researchers had assessed

the possible use of psychotropic drugs as chemical restraints. The assessments were made either by comparing the prescription of psychotropic drugs with the diagnoses of the residents and the treatment guidelines of these diseases or by interviewing the personnel about the reasons for the use of psychotropic drugs. These kinds of studies have been performed in European countries, too. I may tell you that Scandinavian countries have been the most active ones.

The results of these studies performed in institutions show that psychotropic drugs are commonly given to aged residents in nursing homes or in other kinds of long-term institutions: from 36 to 79% of aged residents were treated with psychotropic drugs. Even the concomitant use of several psychotropic drugs is common.

The writers of these 7 articles assessed that psychotropic drugs were used to restrict physical movement or to control behaviour of the residents or for the convenience of the personnel at least in every second case. These results support the conclusion that from about 20% to about 40% of residents were chemically restricted by an inappropriate treatment manner. Thus, chemical restraining is common even according to these kinds of studies.

REASONS FOR USE OF CHEMICAL RESTRAINTS

Factors related to the use of chemical restraints and possible reasons for the use have been assessed either by comparing the medication data from medical records by certain background factors or by interviewing the personnel or by observations in the institutions.

One study showed that the small size of the department was related to the common use of chemical restraints. The small number of care takers compared to the amount of residents was found to be related to the more common use of chemical restraints. The high number of assistant nurses compared to the number of nurses was also related to the higher frequency of using chemical restraints. In addition, low job demands and low job control of the personnel were related to the more common use of chemical restraints. Many kinds of factors related to the behaviour or mobility of residents showed to be indicators of chemical restraining. These included physically abusive behaviour, disorientation, agitation, aggressive behaviour and wandering.

CONSEQUENCES

Chemical restraints have harmful consequences. Firstly, the aged are autonomous individuals. It is ethically questionable to restrict older persons' behaviour and mobility with medications.

Secondly, psychotropic drugs have many kinds of harmful adverse effects. The most common and most harmful side effects are tiredness, memory problems, disorientation, walking problems, incontinence and falls. Thus, chemical restraining may lead to a high need for assistance, fractures due to falls, loss of walking abilities and overall poor quality of care.

Here we must keep in mind that several characteristics of ageing, such as decreased renal function and altered body fat and water distribution, as well as mental or cognitive impairment, make elderly persons particularly vulnerable to drug-related harms. Describing and giving a psychotropic drug to an aged person with memory problems or with dementia may lead even to a total loss of cognitive and physical abilities. Treatments of fractures due to falls caused by adverse effects of psychotropic are expensive.



Participants on the conference

CONCLUSIONS

Although there are not many original studies, these studies show that the use of psychotropic drugs as chemical restraints is common in the long-term institutional care of the aged. Chemical restraining is a hidden problem which is not a common topic in the education or further education of social and health care personnel. This topic is not usually described in geriatric, gerontological or psychogeriatric text-box or in the textbooks of elder abuse, although chemical restraining is a form of elder abuse. I may tell you that our literature search performed in the Finnish medical and nursing literature databases in the Finnish language did not produce any report about this problem in Finnish. I suppose that the term chemical restraining is unknown in many European countries.

PROPOSALS

There is a need for more studies, seminars and discussion papers about chemical restraining. This kind of elder abuse must be prevented. More gerontological, geriatric and psychogeriatric basic education of medical and nursing students and further education of social and health care personnel are needed in order to increase the level of gerontological knowledge and to implement good care practices. We should also talk about possibilities to prevent chemical restraining by legislation – as done in U.S.A. Lay persons, especially ageing populations, the aged themselves, their relatives, lay caretakers and non governmental organizations should be informed about the appropriate use of psychotropic drugs and about the harmful side effects of these drugs. Ethical aspects of long-term care of the aged must be discussed on the political level in Europe.

Lia Daichman [INPEA/ARG]

“REGARDING ETHICAL ISSUES IN GERIATRIC CARE”

A pattern is emerging in long-term care of the elderly that will strongly dominate health care into the next decades. Whatever its future impact, geriatric care will be a proving ground for public policy and social consensus in our ageing society. If care in the community becomes increasingly the norm, the ethical dimensions of this kind of caregiving will call for special attention.

Unfortunately, we still lack historical precedents of care giving role models to deal with chronically ill elderly people over long periods of time. Unluckily, few caregivers have reasonable access to training courses and support groups where they could express their "emotional needs", "legitimate" their feelings, anger, resentment, guilt, love, hate, and all ambivalent emotions inherent to the human condition.

The development of appropriate responses should take into account the need to differentiate among elders who have different levels of competency. It is also important that the practitioner understands and be sensitive to such aspects when making professional judgment about a given case, including appropriate intervention.

Probably, the most difficult ethical issue in some cases is how to balance the elder's right to self-determination against the clinician's belief that something should be done.

The development of a comprehensive dialogue and practical strategies stands as a crucial task and commitment for those concerned with the ethics of geriatric care.

Workshop Report

CORE TOPICS: DIGNITY AND ELDER ABUSE AND NEGLECT IN HOSPITAL CARE AND IN LTC FACILITIES

Key question: European standards on restraint using LTC

This workshop highlighted the issues of mechanical and medical restraints. As presenters showed this issues are not very well mapped especially in the Europe, although they represent a widely spread phenomenon. We need to gain more data about these problems – especially longitudinal data that would tell us not only the prevalence of the phenomenon but also their causes. We also need to inform the hospital stuff about the negative effects of the mechanical and medical restraints, because they are the primary facilitators of this problem.

This workshop pointed out also the issue of informed consent. There is a broad debate about this issue. We all agreed that there is a need of informed consent. We need more deeply debate that would reflect the theoretical as well as ethical issues relating the informed consent that would reflect also the specific situation of elderly people that are not in situation to gain informed consent.

There was a constant appeal in all paper concerning the need of standards of elderly care.

The last highlighted issues were malnutrition of elderly people. We have to recognize that malnutrition is also a problem of western countries. There are an amazing proportion of elderly people that suffer of malnutrition. The data from the UK show that 60 percent of people admitted to hospital suffer from malnutrition. This problem has other serious consequences such as vulnerability toward infection. We need an evidence-based practice that would offer us data about this serious problem. We need to show that malnutrition is also problem of western countries.

RECOMMENDATION:

- Collect data about the problem and prevalence of mechanical and chemical restraints
- To inform the hospital and institutional stuff about the negative consequences of mechanical and chemical restraints.
- To raise the discussion about the nature of the informed consent – especially in the case of people who are not in condition to make informed decision
 - To elaborate standards of elderly care – also for the home care.
 - To highlight the issue of malnutrition in hospital and home care for elderly.
- Create an evidence-based practice for mapping malnutrition in Europe.

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2.3. WORKSHOP:

HUMAN RIGHTS OF FRAIL OLDER PERSONS – INTERCULTURAL DIALOG

Tele-conference Prague – Kiev (available on <http://EU2009.VisualGate.cz>)

Key question: Universal concepts of human rights of older persons versus heterogeneous environment in Europe

CHAIRPERSON: Alexandre Sidorenko [UN/UA]

REPORTER: Petr Wija [CZ]

ASSISTANT: Martin Bohal [CZ]

Dirk Jarre [GE]

“UNIVERSAL CONCEPTS OF HUMAN RIGHTS OF OLDER PERSONS VERSUS IN THE RELIGIOUS HETEROGENEOUS ENVIRONMENT IN EUROPE”

The contribution will start with the concept of ‘human dignity’ and references to the various human rights and fundamental rights instruments and the degree of access people have to them in European society. Barriers to the full enjoyment of these rights, in particular by older persons, will be identified as well as possible measures to overcome them. The role of religious beliefs in this area will be highlighted. Also

the tensions between the respective roles and responsibilities of public, non-denominational and religious organizations will be discussed and practices of good cooperation will be shown.

K. R. Gangadharan [IND]

“HUMAN RIGHTS PERSPECTIVES WITH REFERENCE TO HINDUISM, BUDDHISM, JUDAISM, CHRISTIANITY AND ISLAM; BOOK REFERENCES IN RESPECT OF EUROPE”

It is only recently that the attention of the world community has been drawn to the social, economic and political issues related to the phenomenon of ageing on a massive scale. As the world's population ages and the traditional role of the family as the main support of older people weakens, the elderly are increasingly vulnerable to abuse and various forms of negative stereotyping and discrimination. They often have limited access to health care and face specific age-related restrictions in many fields.

Despite raising of awareness world over, older people still face treatment that runs contrary to most basic rights. Older people face particular difficulties in the following key areas: access to information, community care, decision-making, education and leisure, employment, housing, income, physical and mental health, social care, transport, utilities and consumer protection.

The presentation would involve what the five major religions in the world advocates.

Naina Patel [UK]

“MINORITY ETHNIC ELDERS' ISSUES, RIGHTS AND ACTIONS FOR DECISIONMAKERS”

PRIAE's 10+ years of work and considerable work by its key personnel before then concerns the central issue of securing human rights and dignity of minority ethnic elders nationally and across Europe. Its work has shown that although some progress is made nationally and across Europe, elders from migrant backgrounds who have been contributors to the economy and society at large, in the main are an invisible and vulnerable group whose human rights remain largely unrepresented on the national and/or European political agenda. This

talk with reference to Europe's largest research on Minority Elderly Care (MEC) which involved 3,000 elders from 26 ethnic groups 1,000 care professionals and about 300 community organisations across 10 European countries, will explain the range of long term care issues; the range of infrastructure support particularly from community organisations and propose key messages for rapid action to policy and decision makers to ensure that a growing number of minority ethnic elderly across the EU countries have dignified ageing in 21st century.

3 elders from Chinese background and two faith based elders from Muslim and Jewish backgrounds will explain how coming from a different culture and faith background is impacting on their ageing experience and what their hopes and aspirations are from the EU and national policymakers.

Galina Polyakova [UA]

“EXPERIENCE OF ORTHODOX OLDER IMMIGRANTS GROUPS”

Some experts estimate the number of Ukrainians working abroad as 3 000 000. Official statistics reports only 70 000. This means that the rest are illegal migrants. Although Ukraine has ratified the European Convention on Legal Status of Working Migrants, the situation remains to be rather complicated.

Last year, according to the available data, the majority of Ukrainians were working in Cyprus (11588), Greece (6054), Liberia (4044), USA (2776), UK (2472), Latvia (1559), Russia (1191). However the figures are far from being realistic. Ukraine has already signed bilateral treaties on sphere of employment with 11 countries, however, the employers and, as a result, the employees as well, prefer to act in the framework of shadow economy. Inevitably these entail human rights violation and offence against national and international laws.

One of the most painful problems is the problem with pension provision for people working abroad, especially those using the illegal schemes.

2.4. Workshop:

EUROPEAN STRATEGY TO COMBAT ELDER ABUSE AGAINST OLDER WOMEN

Key question: European Strategy to combat Elder abuse against older women

CHAIRPERSON: Marjan Sedmak [SI]

REPORTER: Lucie Vidovičová [CZ]

ASSISTANT: Lucie Hošková [CZ]

Elizabeth Sclater [UK]

“AGE, GENDER AND ABUSE WITHIN THE CONTEXT OF HUMAN RIGHTS”

Men and women age differently. Despite predictions of closure of longevity gap between women and men, policy and service responses will need to be sensitive to these differences in order to develop effective programmes and deliver quality services to meet need. This presentation will set elder abuse within an international context and outline the work of the Older Women's Network, Europe and other NGOs, to support the Committee on the Convention on the Elimination of all forms of Discrimination Against Women (CEDAW) in developing a general recommendation (GR) on the human rights of older women. A key article of the Convention is the protection from harmful practices, which includes freedom from violence. Once passed, the GR will contribute to mainstreaming gender and age at the heart of the governments that are party to the Convention.

Irene Hoskins [USA]

“SOCIETAL EXPECTATIONS, FRAILTY AND CARE NEEDS OF A GROWING OLDER POPULATION. (THE BURDEN OF WORKING WOMEN WHO CARE ABOUT THE AGEING FRAIL PARENTS/RELATIVES. WOMEN'S LABOUR FORCE PARTICIPATION RATES. RISK OF FAILURE BECAUSE OF STRESS. POSSIBLE INNOVATIONS.)”

Throughout the world, including in Europe and North America, long term care for frail older family members is primarily being provided by women of all ages and predominantly by older women. Increasingly,

it is also provided by women who are balancing employment with care responsibilities as well as by women who have immigrated from developing countries of the South. Most countries, even those with the most developed systems of social protection, continue to struggle with how to provide competent, compassionate and cost-effective long term care to the growing numbers of older persons who need care. This presentation will examine current trends of how countries in both North and South cope with the caregiving dilemma and particularly, how this dilemma affects women. Examples will be given how countries are placing more emphasis on home care; how policies can help women balance caregiving and paid work; and steps needed to better protect women migrating from developing countries to work as caregivers.

Anne-Sophie Parent [AGE/B]

“EUROPEAN STRATEGY TO COMBAT ELDER ABUSE AGAINST OLDER WOMEN / PROJECT DAPHNE”

With support from the European Commission's Daphne programme, AGE is now leading a network of partner organizations to compile a European Strategy to combat elder abuse.

The indisputable rights of older people, as they are prescribed in numerous recognized international texts, will be compiled in a European Charter. A toolkit, addressing each article of the charter, demonstrating what it could mean in concrete terms, and giving practical advice on how it should be upheld will accompany the document.

The charter and toolkit will be developed through a series of national workshops that will bring together the experience and expertise of the whole spectrum of individuals, organizations and institutions that have a role to play in care for the elderly.

The charter and toolkit will attempt to address all aspects of elder abuse, and issues that are relevant to both sexes.

The project runs until December 2010.

Workshop Report

European Strategy to combat Elder Abuse against Older Women

KEY QUESTION: EUROPEAN STRATEGY TO COMBAT ELDER ABUSE AGAINST OLDER WOMEN

ARGUMENTS:

Diversity of older people: Old age = life span of 50+ years and heterogeneity according to race, disability, sexual orientation, ...

Need for long term care is and will be increasing (prevalence of Alzheimer disease,...)

Care is provided mainly by women (70% vs. 30% by men), and mainly by informal sector, which is priceless but not costless.

Due to feminization of old age there is a problem of a) care provision for older women and b) women as care givers because men and women experience ageing very differently.

CHALLENGES:

- Not enough evidence, not consensual definition available
- Cultural differentiation of understanding what is violence
- Issue of migrant women carers – brain drain, not satisfying work conditions.

RECOMMENDATIONS, SUGGESTIONS:

- Rising awareness of all types of violence on elderly people and women especially.
- Involvement of older people in policy making and quest for solutions.
- To continue with the work started regardless of not sufficient empirical evidence available.
- Harmonization of research tools, reporting systems, and definitions on national, international and EU-level
- Translate existing Charter on rights of older people especially women into documents which are used (make use of toolkits and consultations)
- Provide shadow reports on governmental initiatives to combat elder abuse
- Attract young people to take part in search for solution, in campaigning, etc.

- Continue in the search for sound evidence, do more prevalence studies, and studies how are services for abused women are effective
- Compare and share results within countries, make them available and understandable for civil servants
- Do not accept compromises: violent is violent, abuse is abuse – it hurts
- Make guidelines for quality care mandatory on EU level: it will raise the value (social status and financial rewards) of care providers, therefore may attract more men in this positions etc.
- Antidiscriminative directive valid for outside the labour market
- Spread the responsibility over solutions on various actors
- Make labour markets more friendly for caring women
- Harmonize education on gerontology and geriatrics

3. WOKSHOP

3.1. Workshop:

RIGHT TO CHOOSE THE PLACE FOR LIVING – LIFELONG HOME FOR THE FRAIL ELDERLY PEOPLE WITH DISABILITIES

Key question: Good practise examples multiplication. How to do it?

CHAIRPERSON: Anne-Sophie Parent [AGE/B]

REPORTER: Giovanni Lamura [IT]

ASSISTANT: Klára Cozlová [CZ]

Jan Lorman [CZ]

“COMMUNITY LIFE AS A BASIC WAY OF SOCIAL INCLUSION OF THE ELDERLY”

A. How are the key stakeholders responding to the age friendly community life?

Our actions need to be influenced by the experience of the most elderly among our fellow beings. They are the only ones who really know the problems of older age. I prefer the view of a mature man or woman, who is at the end of his or her life pilgrimage. These are the people

whom we have to ask for answers to our questions. Complicated questions may have simple answers – and the other way round: questions which may sound simple to people of younger age may have the hardest solutions of all.

I regard SENIOR CITIZENS THEMSELVES, and above all the most elderly among them, as the first stakeholders.

The second are the FAMILIES in which are living some of the elderly. The first experience about the intergeneration respect and cooperation we have obtained in the family. On the other hand the family may be quite toxic environment for the elderly.

Third stakeholders are ORGANIZATIONS OF OLDER PEOPLE, whom I divide into two types. The first are passive advocates of the interests of senior citizens. They resemble trade unions. The second types are those which I would call “pro-senior” organizations. Their chief product is specific assistance given to older people or their close relatives. They improve the quality of their clients' everyday life. I value most of all such organizations which represent a logical and harmonious combination of both these types – those which create services and programmes for individuals (of the self-help kind), accept responsibility for the current state of affairs and in this position also strive to provide better conditions for everybody.

SCHOOLS, which should teach children about older age and its problems, to lead the youth to voluntary cooperation in the community, do so only sporadically.

CHURCHES are creating a community of its kind; they have a specific leader and authority: God. They care for the principles of living together; they measure our deeds with the will of God. The confessors know our sins.

VOLUNTEERS: Without their fervour for mercy (not sacrifice!), for pain and joy of others which they consider to be their own as well, the community would be just grains of sand without any binder, without cement. They are the cement of the community. Of great importance is the development of community programmes, involving professionals and older people themselves in their creation – programmes which obliterate the difference between a “healthy” and a “disabled” person. Communities are well able to substitute for some functions of poorly-functioning, fragile or abusive families.

In my experience, POLITICIANS and policy-makers suffer from lack of information about the problems of older age. Therefore they can not make good decisions, and they often underrate older people – perhaps with the exception of the pre-election year. It is a solace to me to speak with a politician who has experience with care for his or her parents who depend on it.

Socially responsible COMPANIES and corporations can grant financial assistance. Its employees help work as volunteers.

ACADEMICIANS, universities possessing educational and research potential ... research centres and independent experts, of course ... they show initiative, they look for new orders. Their importance has been growing, as grows their readiness to consult and come to an agreement even with informed lay persons.

Let us not underestimate the importance of SERVICE PROVIDERS for senior citizens, but also health and social insurance companies, which significantly influence the sort, quality and extent of the care provided. Older people are the majority recipients of these services. We have to involve the transport accessibility into this category.

THE POLICE ... There is nothing worse than a policeman who is unable to recognize domestic violence against the elderly.

DOCTORS are for seniors often the highest authorities; they obey them as children obey their mothers. They border and structure our life. The family doctor is the herald of the beginnings and endings of our lives. He is also a gerontologist (not only a geriatrician). He knows the stem of our life. He heals, he influences our regime, and he recommends lenitive treatment.

Why am I listing so many stakeholders? Because the necessary changes can not be achieved without joint action cutting across the whole of society; isolated actions will have slow effect. Laws can only define the framework for our behaviour; campaigns of organizations of and for older people may arouse misunderstanding or even aversion.

B. What are the barriers to, and opportunities for, development of community life on ageing society?

First of all the key factors are both the role and social status of the elderly. We would start from several questions:

- Do old people have anything to contribute to our society?
- Do we think that there is some age line between a “productive” and a “post-productive” age of man?
- How much do we value our life in older age?
- What role do we ascribe to this period in our life?

According to Tamara Tosnerova there are the <Age-related prejudices>

1. All old people are the same
2. There is no difference between old men and old women
3. Old people have nothing to contribute to the society
4. Old age is fragile – old people need to be looked after
5. Old people are an economic burden for the society

[in Tamara Tosnerova, Ageism in practise, 2005]

I have seen slackers in their thirties and diligent workers of 80 years, and the other way round. We got used to parcelling out life to effectively manageable parts. We have maternity hospitals, hospitals, old people's homes... We have doctors for knees, ears; we have factories for batteries, for bearings... but we miss the meaning of the whole and its context.

CONTINUUM OF LIFE AS AN INDIVISIBLE WHOLE

Old age is a natural stage of life. It has its specificities which distinguish it from other life phases. The general characteristics of old age, as defined by the industrial society, perceive the post middle-age population as a labour force of declining abilities. This paradigm influences the current view of post middle-age. I do not deny the importance of work nor do I challenge its psychological and social value for the humankind: life without work, as a form of creation, is meaningless. But the current concept derives from the demands of ever-growing consumption which dictate a constant increase of the productivity of labour and dominate efforts for high performance and market success. This brings the need to succeed in competition, hence a further explosion of consumption, because products have to be sold with the help of promotion, advertising and sophisticated marketing.

OLD AGE IS REGARDED AS A LOSS OF STRENGTH, a decline of abilities which have to be compensated for by new energy, new forms. “The place for old things is among scrap.” Renovation is a desire and a goal.

First of all we have to renovate our environment, disowning and outdoing our predecessors, in order to return to some of their values in the next generation. But we do it at a time when they do not threaten us as our direct competitors. That is why we often get on better with our grandparents than we do with parents.

Guided by a desire for maximum effectiveness and performance, the industrial society DIVIDED HUMAN LIFE INTO STAGES and invented another product called social security; social solidarity with the weaker ones. A good and praiseworthy idea, no doubt – but how do we understand it? In ethical or economic terms? Take the self-confident, successful thirty-year-old near-supermen of today, and confront them with the fact that by their work they provide for old-age pensioners. No, not all of them are cynics, but while some open their wallets for the sake of targeted solidarity, others regard pensioners as parasites. Particularly in recent years, when the media dish out demographic data testifying to a changing tree of life and create catastrophic scenarios about mandatory expenditures of the state budget and increasing tax burdens imposed on the productive population cohorts in favour of the non-productive ones, an ethical analysis of the relations between different generations is totally absent.

Our *raison d'être* does not lie in productivity; PEOPLE CANNOT BE REDUCED TO LABOUR FORCE, as economists like to do. THE ULTIMATE GOAL OF HUMAN LIFE IS MATURITY, with all it involves; and our lives become fulfilled when we end our days on this earth. Not until then are we able to grasp life as a complex whole, to evaluate the importance of its parts and feel satisfied. Much suffering is required for understanding that not everything has been lost. Old age is a period of joy and happiness just as it is one of worry and pain, which does not always turn out the way we may have imagined.

Evaluating lives comes to an end and involves extraordinary superciliousness and contempt characteristic of the age of pubertal romantic pomposity, when everybody and everything older than ourselves seem to us inept and backward. Some people retain pubertal approaches for dozens of years. When we are in the ascendant and until we experience pain, we are unable to appreciate beauty. We are mean because we put ourselves above all others.

But true generosity stems from shortage, not from surplus. I refuse to describe the second half of life as “post-productive”. This term is based on the concept of humankind as highly talented robots who do not understand

that even if the world changes beyond recognition (as a result of new technologies, globalization etc.), its essence will always remain the same.

The presented statements characterize the position of the elderly in the Czech Republic. The way we prepare for old age shows how seriously we take it.

Statistics prove that few people manage to get ready for old age. Perhaps they do not even regard ageing as a problem or they edge thoughts of it out of their minds. For many of us the onset of old age represents a limit, an official economic and organizational category called, “pensionable age,” which we view with the same sort of detachment we feel when watching a television story. We believe that we do not need the experience and advice of our older fellow men and women because they are “inept and backward.” As if the elderly belonged to a different world.

Hence the difficulty of introducing a new paradigm of old age based on the lesson learned about those added years which, we find, it is so uneasy to fill with life of good quality and purpose.

People under thirty do not plan for their old age. Nothing compels or motivates them, nor are they encouraged to do so by their parents, grandparents and teachers. This ABSENCE OF PROJECTING ONE'S OLD AGE has a significant impact on the decision-making processes such as defining government policy, drafting legislation and designing practical steps implemented by civil servants and officials of local self-government bodies. These phenomena, which originate in the minds of each one of us, find their expression in public policies. Essentially there do not exist any discriminating laws – only such that do not recognize and respect old age.

Old age is a status, yet it often seems not to exist at all. The elderly play a “role – non-role”. Old age and ageing are approached irresponsibly, as is evidenced by the results of surveys inquiring about the way people prepare for this stage of life. Only a negligible percentage of people make preparations for old age. Most rely on the help of society, which they expect to look after them if they find themselves in material or social distress or when their health deteriorates. They transfer responsibility for their old age to someone else. This may be an inherited pattern of behaviour, still typical today of the middle-aged generation who know it from their youth. It is supported by the current policy of

the government, which has failed to come closer to pressing home the idea of every individual's personal responsibility for his or her future, including old age, in any of its social doctrines, let alone in practice. The welfare state acts as a reliable safeguard – sometimes a very costly one – in case of material distress. It deals out generous benefits even to those who shy away from work, supporting their passivity and egoism. It pays out sickness benefits without adequate control of observance of a therapeutic regimen by their recipients.

Care versus independency

Adjusting to extraneous influences makes us passive in old age, because we don't want to bother anyone, because it's supposed to be so, because old people are poor, because it should be so, they dress inconspicuously because it should be so, they are second-class citizens because it should be so, it is pauperism.

We adjust to the myth that old age is an object of care and not an independent subjective creator of history.

The right of election and other general human rights are often denied because a fragile old person cannot defy himself. We deny them owning of one's self as basis for individual responsibility for their own lives.

TOTALITARIAN POLITICAL SYSTEMS TAKE AWAY THE CITIZENS' RESPONSIBILITY FOR THEMSELVES; they take away the responsibility of the family, of the community. Why? Because they already have taken away the owning of one's self of each of us. In totalitarian regimes everything – people and property - is the property of the dictator or dictatorship.

How, in this situation, should old people become a part of the mainstream community? Do old people have a right to own themselves, be a dignified and equal partner to others? This question is of no effect! Human beings have the basic right to be themselves. This right is undisputable. The caring professions must respect this right. In other words they must not let people live in undignified conditions, put them down or to consider them an object of their care only.

C. Community life on ageing society – why?

ONE OF THE MOST IMPORTANT HUMAN NEEDS IS THE NEED OF A RELATIONSHIP; WE WANT TO “BELONG SOMEWHERE.” In old age this need, and mainly its emotional content, grows more important. Another reason why we need others is that we need new information and learning.

ALSO THE NEED TO ACCEPT HELP FROM OTHERS IS GROWING, OR JUST THE FEAR OF THE INEVITABILITY OF THIS HELP.

We are losing direct interpersonal relationships in middle and old age. Children leave their parents to start their own families. Our flats become empty. Our parents and friends are dying. People become afraid of staying alone, and this can hold us for years in painful emotional models. We are afraid to set the limits of our personality out of the fear of living a life without love. Paradoxically the setting up of our limits decides whether we are a subject of our own life or just an object of others. THESE BORDERS LIMIT THE TERRITORY OF OUR RESPONSIBILITY. Setting up the borders and accepting responsibility saves lives. (Proverbs. 13,18,24)

THE RESPONSIBILITY FOR RELATIONSHIPS IS A WHOLE-LIFE TASK. Apostle Paul says: “As you saw, so shall you reap” (Galatians 6,7). The basis of the community is direct interpersonal relationships; generational relationships, intergeneration or group but also relationships of individuals. SOCIAL EXCLUSION IS A RESULT OF THE RELATIONSHIP CRISIS. To be in the mainstream of society is the result of our relationships but also of the quality of the relationships in the community.

The local framework of community.

The kind of society I write about is defined locally. It is a genius loci of the city, the metropolis, the village.

I mentioned a few stakeholders with the deciding role for active ageing. Does this mean that also the society is just a random mixture of these? Surely not! EACH OF THEM HAS A DIFFERENT ROLE IN THE COMMUNITY but at the same time has its role in his own professional, non-formal group (doctors, family, police crew, etc.) Each of these units has its authorities and leaders. An example for this is church communities. In the same way no community can exist without its authorities, without a vision, a leader. It is useless to think that any community can

function well without a vertical and a horizontal structure as a formless mass only – as protoplasm.

Community is a group of people with personal borders. Its relationships must be given reciprocity, one for another, and at the same time everyone for himself. Important is the principle of giving. By giving a gift I show a relationship to someone else but from the accepted gift I myself can profit; self-help and mutual aid. GIVING IS JOY AND BENEFITS THE GIVING PERSON AS WELL AS FOR THE RECEIVING ONE.

It is the same with a community on a local plan which is a COMMUNITY OF OLDER PEOPLE AND THEIR FRIENDS.

THE CONDITION IS FREEDOM AND FREE WILL OF THE INDIVIDUALS – OF ALL PARTS OF THE COMMUNITY.

D. Practical example of a community programme. Community centre “PORTUS House” in Prague – Czech Republic

THERE, IS A 3-STAGE MODEL:

- Centre of activation programmes: The Academy of Seniors (education, culture, physical exercises, and hobbies), Volunteers’ Centre, Seniors’ Theatre and Senior Café Bar.
- Social care and intervention services: home care and home help, non-stop crisis line (free charge), advisory, diet canteen, physical hygiene, transport services for handicapped seniors, senior bazaar
- Social-health services: distress care (non-stop monitoring, quick crisis help, health advisory, psychotherapeutic support), home care centre, respite care centre with rehabilitation care, lending office for compensation aids, physiotherapy, denture services, memory training
- Community centres for coordinating of professional provision of services with self/help activities

This community centre was established by the senior civic organization Život90 – Life 90 in 1990.

E. Can the active ageing concept also be developed to allow for better intergenerational connections in communities? Czech experience.

SUPPORTING THE CONCEPT OF RESPONSIBILITY OF THE COMMUNITY; the sort of responsibility the communist regimes took away. Supporting THE CONCEPT OF LIFE-LONG HOME. SUPPORTING THOSE TYPES OF CARE WHICH MAKE IT POSSIBLE FOR OLDER PEOPLE TO REMAIN IN THEIR OWN FLATS AS LONG AS POSSIBLE. Home care, respite care, alarm systems. Let us remember the tragic consequences of disastrously hot weather and the floods. How many human lives could have been spared if there had existed functional alarm systems. These services support the cohesion of the community, and COMMUNITY COHESION IS A MEANS OF BETTER UNDERSTANDING FOR THE PROBLEMS OF OLDER AGE, supporting the concepts of palliative care.

I regard it as deeply wrong to use the methods of technological division of labour created by the industrial society in inter-personal relations. We have created institutions to deal with problems. We have institutions for birth, illness, old age, dying ...The present-day generations lack immediate experience with dying and death. Dying in hospital, deserted by our dear ones, is dreadful. Perhaps the reason why we do not criticize it enough is that those who are condemned to this sort of death can no longer protest.

F. Conclusion

WE SHOULD TRY TO MAKE THE ENDLESS RING OF HUMAN LIFE INTO ONE WHOLE; BIRTH, CHILDHOOD, ADULTHOOD, OLDER, OLD AGE, AND DEATH. We should grasp the fact that old age is the future of each one of us; therefore it is necessary to get ready for it. Out of sheer selfishness it pays off TO EXPLORE THE STORIES OF THOSE WHO HAVE A QUITE A BIT OF OLDER AGE BEHIND THEM ALREADY. This is the solution. Its execution is just as endless as the history of the human species. But I do not know a better solution. The indisputably decisive role in the solution of the problems of older age is played by older people themselves. No-one can play it in their stead. THE COMMUNITY LIFE THERE IS THE GOLDEN OCCASION TO DO IT.

Active senior citizen organizations can play the role of an intermediary who knows how to identify and listen to the voices of the weakest

among us. Active senior organizations must be included among the engineers of such changes.

Promoting the idea of personal responsibility for their old age, such essential changes can only be achieved through the joint action of the entire society.

Getting old is normal. However, ageing well is a great art, which deserves our admiration.

Workshop report

Right to choose the place for living – lifelong home for the frail elderly people with disabilities

Ad. 1

WHO PROJECTS: AGE FRIENDLY CITIES, HEALTHY AGEING, AND AGE-FRIENDLY PRIMARY HEALTH CARE CENTRE?

by AGIS D. TSOUROS

Aging doesn't get attention it deserves, because of primary concern on the other things, even in WHO. Many subjects which can affect aging (consequences of financial crises, pandemic, economic of health system – always highest price pay poor and older people)

Strategy to take to provide comprehensive policy and support for older people:

- Importance of local action
- Settings
- Gear of local government

We don't think about our health before we get into the stage it is already problem. Good investment into health is not seen as good...

To generate strong political commitment for aging.

4 OBJECTIVES WITH WORK WITH LOCAL GOVERNMENT:

1. Rise awareness to health aging – create condition for changing minds about aging and aging society (out of prejudice and miscon...)
2. Active involve/engage older people – consultation, empowerment – to show it make difference, to make older people the voice (listen to, being independent)

3. Creating health environment – if city is fit for older people it is fit for everyone (idea of house, neighbourhood, security, streets are good, no architecture barriers)

4. Promoting accessible care and health services – physical accessibility, services

ACTIVE LIVING IN LOCAL SETTING –

To bring around the table all those who are interested, connection between all. Healthy aging strategy is important for gerontologist, nurses, architects and so on... not only for those ...-ist.

Ad 2.

THE IMPORTANCE OF MUNICIPALITIES IN SUPPORTING THE FRAIL ELDERLY – THE SWEDISH EXPERIENCE

by BARBRO WESTERHOLM

Housing – get blue leaflet. Research made by Swe ministry of Health and Social affairs on Housing of Old people. State take care of the old people, services with quality services – municipalities are responsible for social services too and for housing and health care.

RESPONSIBILITY: state, municipalities and country – problem to coordinate.

LIVING FORM: flats, house, shelter house. Homecare services can be offer for regular houses or shelter houses. Elderly should be able to continue to live in their own house as long as possible.

BUT not all people do want to stay in their house, you can may be a prisoner in your own house (bathroom is too small, no possibility to go out) – you want to move out. There is a lack of places for dementia or people who are not ill so SWE had to cope this problem.

Society should respect people who decide of their vote where to live! Even when they decide to move out.

Senior housing – become more and more popular (accommodation within housing) – for people in certain age (55-70), possibility to do things together

- Special housing – nursing homes - people with dementia usually use them, medical service is around
- Shelter housing – elderly who feel anxious or insecure and are too well

to get to special housing. Is only for renting, it may reduce burden on special housing and reduce total costs for the elderly

- Small flats for renting – regular houses, community help to get, community alarms, care and services
- Social content of the day – meals should be highlight of the day, animals (dogs, cats, pigeons, rabbits can make a change mainly for dementia, people go outdoors with animals even before they refused to do so), culture – in and outdoor activities according to possibilities and preferences
- My home is workplace of someone else – how to make healthy workplace, personnel safety and privacy

CHALLENGES

1. Minorities – some culture – say we take care of our older people ourselves – it is different focus..
2. People with special needs (deaf and blind, rare disease)

AVOID CHANGE OF HOUSING, AVOID SENDING TO HOSPITAL – BUT THE QUESTION – TREAT? Or empathy?

SHOULD BE TREATED WITH EMPATHY AND RESPECT TO THEIR DIGNITY.

AD 3.

COMMUNITY LIFE AS A BASIC WAY OF SOCIAL INCLUSION OF THE ELDERLY

by JAN LORMAN

Who are the different stakeholders responding to the challenge of active ageing?

– the most elderly among our fellow beings, seniors themselves, families (but problems with „toxic families“), organizations for older people (quality standards of services), schools (create backgrounds and people taking care), churches, volunteers, politicians, companies, academicians, service providers, police, doctors

Community could substitute families, organizations in some way! So, social responsibility campaigns makes sense.

WHAT ARE THE BARRIERS TO, AND OPPORTUNITIES FOR, DEVELOPMENT OF COMMUNITY LIFE ON AGEING SOCIETY?

- AGE RELATED PREJUDICES:

1. all old people are the same

2. there is no difference old men-women

3. nothing to contribute to society

4. fragile

- CONTINUUM OF LIFE AS AN INVISIBLE WHOLE – old age is regarded as a loss of strength, stage are divided according to labour – old are not labour force, ultimate goal is maturity, there is absence of projecting on's old age (OLD AGE IS STATUS) , they transfer responsibility for their old age, welfare state acts as a reliable safeguard

- care versus independency – owning of one's self is basis for individual responsibility for their own lives, totalitarian political systems take away citizens' responsibility for themselves, basic rights to be themselves, to decide of them-responsibility for oneself

Photos of community centre PORTUS HOUSE in Prague, by Život 90.

CONCLUSIONS:

- WE SHOULD TRY TO MAKE ENDLESS RING OF HUMAN LIFE INTO ONE WHOLE – birth, adulthood, older, old, death.

- explore the stories of older

- decisive role in solution of older age is played by older people themselves

- community life there is the golden occasion to do it

- promoting the idea of personal responsibility for their old age

Ad 4.

DYING IN PLACE – RIGHT TO CHOOSE THE PLACE FOR DYING (PALIATIVE ASPECTS OF THE LONG/TERM CARE)

by LADISLAV KABELKA

V češtině:

- envy SWE and WHO – because czech republic has not sufficient possibilities for elderly people to live in their place (lifelong continuum has to be seen as a whole)

- palliative care is a possibility how to help people to live till the end in their place

PRINCIPLES OF PALIATIVE CARE – always could be done something,

problem is not only „patient's“ but for all society, we shouldn't overlook multidisciplinary, biological, ethical, spiritual needs. Not curative medicine, but palliative – it is not one or other, but to go hand by hand – to provide the best services as possible.

Demographic trends show the need to be ready – but unfortunately, nobody is ready for future needs in Czech Rep. People died during hospitalization in hospital, in hospices, but only in their home/social services it was only in 29%.

Ageing and disease – we are not able to cure all diseases, heart failure is more often with rising age (oncologic disease, dementia), there are usually chronic illnesses, so the goal is holistic model of care, natural social environment as a part of care and standardisation of medical treatment.

Palliative care at home settings – it is possible, there is need of respect of wishes of patient, family and society --- is it possible to coordinate?

It is necessary to take care: Natural social relations, support, spiritual needs, bereavement care

It is necessary for future: to have mobile specialized palliative care unit, holistic model of care, cooperation with GP, education in specialization

QUESTION AND REMARKS

AGE FRIENDLY CITIES – REALITY FOR IMPLEMENTATION OF CHANGES IS VERY DIFFICULT, SORT OF PLAN OF 10 YEARS AHEAD?

WHO – makes local contract on health cities with government and local responsibilities (City of Stockholm for example, played important role)

FINANCIAL ARRANGEMENT – what is offered in SWE and what is income?

People pay for home care and daycare. The rest is paid by taxes, in special houses, nursing houses is the rest paid by municipalities.... The problem is how much should be paid by municipalities and government.

KEEP NOT MOVING OLDER PEOPLE TO OTHER SETTINGS – BUT HOW COULD IT BE CHALLENGED?

How you will organize moving, how you will do it. There is possibility to get oxygen to home with nurses and to take care of people over-

night (people shouldn't be forced to „do something for my dad“ even if he doesn't want to go to hospital, to be cured and so on...) We have to have palliative experts, but even to spread basic knowledge between all interested and all involved. Even because it is less expensive.

SHOW ACTUAL EXAMPLES OF COMMUNITY LIFE IN CZ?

Community life is very difficult, because relationships between people are destructed by planned economy and people are not ready to take responsibility. "

Forms for community life are not really ready. Geriatric nurses were working, but it was stopped so they are not working any more ... instead there is homecare and social services... but homecare is not sufficient, similar social services are not sufficient and not well financed. There is no framework of synergy, of working together and of community planning at all. This should be founded by regional finances, but it deserves even more attention.

LANGUAGE AND CULTURE DIFFERENCES – GOVERNMENT PROVIDE IS NOT EQUAL FOR ALL IN CHINA, DOES IT WHO SEE? HOW DO YOU HELP DIFFERENT COUNTRIES WHERE ARE ETHNIC MINORITIES?

Public health include healthy ageing. They exist inequality between east west and they could be reduced. For all citizens.... On websites healthy ageing publications are in there. The myth of healthy ageing, developing of healthy profiles of healthy ageing.

We were working on quality care – did collaboration with centers with palliative centres, they are very popular in there, to develop quality palliative care.

Just a point – would it be possible to make available presentation? Some experiences of home-palliative care in CZ?

Social and health is divided and it is very difficult to put it together, people are not ready to see necessity of providing holistic approach. Maybe it is problem in CZ, but.... there are some mobile palliative teams, but only few.

Note – I work for older people, when I travel in Australia, there was dying private thing and elderly people rent houses and buy caravans and go around Australia till they die. It is culture. It depends even on our possibility of approach to die, to the end of life.

Personal experience, but not all people could do it.

3.2. Workshop: Old age, care and dignity

Key question: Concept of Elderly Dignity and difficulties in its implementation

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REPORTER: Pavel Weber [CZ]

ASSISTANT: Martin Bohal [CZ]

Zdenek Kalvach [CZ]

“Active dignitogenesis and the concept of Elder Dignity Abuse and Neglect – EDAN”

At the beginning of the 1960's the battered child syndrome was formulated in paediatric medicine; this was later expanded into the concept of child abuse and neglect.

In analogy to the negative phenomena in children, dependent on care and more vulnerable, a similar issue was identified about 10 years later for similarly dependent older people reliant on the help of others and with a limited ability to defend themselves and with an ambivalent relationship to those hurting them from their immediate surroundings (family). One of the first articles describing physical cruelty (beating) towards an elderly person as part of domestic violence (granny battering) was published by J Burston in the British Medical Journal in 1975.

At the same time for senior citizens the concept was widened from physical violence to include other forms of inappropriate harmful behaviour such as elder abuse, or more exactly elder abuse and neglect - EAN. Today its principal and generally accepted forms include physical violence, mental abuse and neglect, sexual abuse, financial abuse and neglect (including so-called self-neglect).

It has been shown that this is a multi-level problem often with poorly defined boundaries. There exist, for example,

- Events, systemic, repeating - but also casual
- Causes, manifestations and general connections, generally valid and understandable, but also special, specific ones, conditioned by circumstances, relationships, traditions and norms which may be special, local (family, community, cultural), including some problems in families and in migrant communities.

- Gross, indisputable, extreme forms - and also borderline, disputable, socialised, considered by many to be a wider behavioural norm (to qualify as abuse Czech legislation requires repetition of the behaviour, suffering on the part of the victim and a generally understood level of seriousness and danger).

This complexity and multi-level character blurs the boundaries, leads to misunderstandings and complicates international comparisons and agreement on suitable interventionist and preventative measures, on the justification for and limits to social control.

There exists

- A level of serious and undisputed guilt - the conscious criminal harmful behaviour with criminal accountability which we encounter for example in anomalous individuals-aggressors with personality disorders, mental disorders or drug or alcohol dependency.
 - Gross and repeated physical violence.
 - Sexual abuse
 - Financial abuse
 - Gross neglect of a dependent person linked to evident suffering on their part (starvation, hypothermia, dehydration, pain, non-treatment of injuries)
 - Gross humiliation and insults
- A level of errors and inappropriate behaviour under stress, from overwork, failure to cope with conditions, without help (inappropriate behaviour is often accompanied by feelings of guilt)

Burn-out syndrome

A caring family left without advice, support and supervision

Lack/overworking of staff in nursing homes ("common neglect", excessive use of physical and chemical restraints)

- A level of ignorance of the needs of frail, at risk clients and a kind of everyday meanness in relationships

Faulty stereotyped views on the approach to caring for dependent people and clients

Inadequate knowledge of their specific needs and care risks, including inadequate information on frail geriatric patients and the threats

to them, e.g. in hospital care - a cause of suffering is not ill will on the part of carers but their lack of knowledge of the specific needs of frail clients.

Discriminatory rules, ageism, socially acceptable marginalisation of the elderly while minimising their needs and problems.

One of the basic conceptual problems in the approach to this complex, fluid and in some respects vaguely defined phenomenon is whether to consider the relationship of the social norm (normal, correct, desirable behaviour) and social pathology (various forms and displays of Elder Abuse and Neglect - EAN) as a dichotomy or a continuum.

In a clear dichotomous antimony problems of course arise with international and inter-cultural interpretation and standardisation.

For this reason an introduction for gerontology and the EAN issue might be the approach taken by clinical medicine and the World Health Organisation, which regards the relationship of health and disease as a continuum. A significant part is played by the fact that

- Etiologically and pathogenetically clearly defined diseases can occur not only in a manifest manner with a classical clinical depiction, but also inapparently, inconspicuously, sub-clinically
- In addition to etiologically and pathogenetically defined diseases (the disease model) health problems also exist which are ill-defined and unassignable even with careful investigation to any particular disease - an important component of this ill-health outside the disease model is the issue of geriatric frailty, involuntary deterioration and multi-causal geriatric syndromes.

Also helpful is the attempt to support health taken as being "more than the absence of disease". This process is designated salutogenesis.

If gerontology wishes to learn from clinical medicine, it should accept the continuity of the relationship and the transition of "normal behaviour" in respect particularly of mild forms of neglect and abuse (which can however have fatal consequences in spite of their inconspicuousness). It would then be possible to encompass the issue of people who do not feel comfortable or safe in a certain relationship, in certain care, in a certain milieu, even without the presence of concrete forms of abuse and neglect.

Through the use of the continuum idea it then becomes appropriate to replace the concept of EAN with that of EDAN - Elder Dignity Abuse and Neglect. For dignity appears to be the most significant life value, the most significant entity to which attention should be devoted in the care of frail disadvantaged clients. It thus becomes the concretisation of living a positive norm, the analogue of health in relation to sickness.

The analogue of support for health salutogenesis (over and above prevention of, intervention in and even eradication of diseases) should then be the process of actively supporting and renewing dignity - dignitogenesis, particularly for disadvantaged frail elderly people in risk environments, including various forms of institutional care.

The concept of a continuum perception of EDAN would, inter alia, permit us to include (investigate and intervene in)

- Very frequent minor expressions and changes - shifts within the continuum which cannot be classified as the first expressions of dichotomously differing nature
- Early warning signs
- Loss of respect
- Lack of interest in the client or a family member
- Diminution of competency, infantilisation
- Reduction in the sense of security and social and relationship satisfaction
- An atmosphere of ageism
- The inconspicuous start of fatigue and listlessness on the part of carers, beginnings of an aggressor's path.
- Circumstances offering temptations for inappropriate, insensitive behaviour, risk factors, analogous to the risk factors of pathogenesis in disease development.
- The character of the needs of people undergoing neglect at the level of disrespect, loneliness, loss of purpose - but not reaching the level of punishable neglect or humiliation and abuse.
- Culturally condition norms for relationships, behaviour, care standards (a global approach to regional specifics)
- Strengthening of dignity as a social norm, social health.

The concept of EDAN thus includes the aspects of the perpetrator (intention, guilt, support, knowledge), of the one who suffers (the nature and degree of suffering, feelings, expectations, own fault), of further development, forecasts (risks, risk factors, the progression of deprivation and inappropriate behaviour), of context and degree, of early identification and prevention, of the growth not only of an ageist, but also an actively created anti-ageist atmosphere in society.

The concept of EDAN can be significant in attempts to improve the quality and general conception of long-term care. In fact there exist two concepts of the care and general approach to frail and disadvantaged senior citizens and geriatric patients - clients of health and social services:

- An existential (holistic) concept of support for a purposeful life for human beings.

Dignity is a basal prerequisite and the highest value of a system of services and support perceived in this way.

The EDAN continuum of dignity, abuse and neglect is fully applied.

Dignity is not only to be prevented by the elimination of inappropriate behaviour but also actively strengthened and renewed through the process of dignitogenesis.

- A biological economic (reductionist) concept of low-cost care for basic biological needs (supported by demographic panic, an ageist social atmosphere, by fears that there are insufficient resources for high-quality care for increasing numbers of senior citizens)

Dignity is a marginal, luxury value.

There is identification and intervention only for major forms of abuse and neglect.

The quality of care does not include a meaningful existence of the humans in care and takes no account of their natural social roles.

The existential concept of EDAN also includes in the care of frail geriatric clients suffering from reduced dignity, respect and self-respect, from the break in their life ("it's not me anymore" - reduced dignity of personal identity), from loss of purpose, from communication and stimulus deprivation, from loneliness and unsatisfactory participation, from the feeling that a person has become a burden and has lost face. This is an enrichment of the original understanding of EDAN with the postulates of VE Frankl

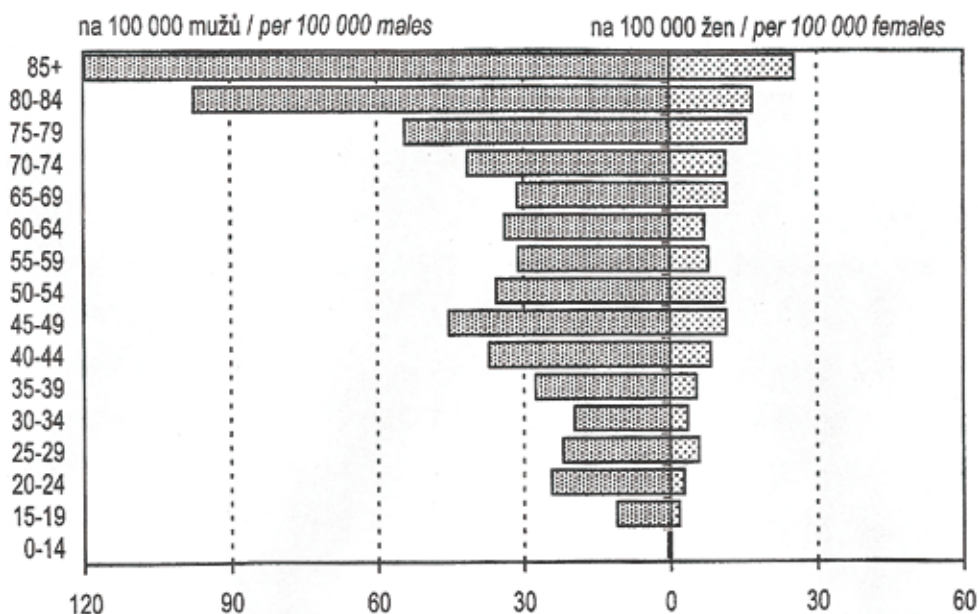
(the meaning of life, the need to support hope, courage and the search for meaning in life even in serious health and functional difficulties), the aforementioned A Antonovsky (sense of coherence) and A Maslow (transcendence, hierarchy of human needs). The EDAN concept applies new paradigms of medicine to the issue of elder abuse and neglect.

The concept of dignitogenesis - analogous to pathogenesis (the development of disease) and salutogenesis (the development of health), designates a set of systematic methodological individualised measures supporting a meaningful life, a social context for care and self-respect for frail disadvantaged old people. This is not just about not destroying or disrupting dignity, but also about actively reconstructing and strengthening it.

A clear call for the development of dignitogenesis is the suicide rate for the elderly, the chief cause of which is considered to be precisely this loss of purpose and self-respect, and the sense that a person has become the burden referred to (see Table 1).

Table 1: Suicide rate per 100 000 inhabitants by age, Czech Republic 2001 (Source: Institute of Health Information and Statistics, Prague).

Sebevraždy na 100 000 obyvatel podle věku (ÚZIS ČR) 2
Suicides per 100 000 inhabitants by age (IHIS ČR) 2001



Win Tadd [UK]

“Dignity of the frail elderly people and the risk in health and social services”

The right to, and the need for, dignity is frequently cited in European policy documents relating to the health and social care of older people. In the UK a series of MORI surveys undertaken between 2004 and 2008 to understand public and user attitudes found that there was a strong correlation between the extent to which people feel they are treated with dignity and respect and their overall perception of services.

There is also research evidence that positive health and social outcomes result when people feel valued and respected; are involved in care decisions; maintain a positive self-regard, and are able to exercise direction over their lives. Furthermore, once dignity is ignored, there is a danger that neglect and disregard will become the norm and that staff morale will plummet, as they are “brutalized” by “uncaring” systems. Such consequences have been routinely uncovered in investigations into patient abuse.

A recent W H O general population survey undertaken in 41 countries showed that dignity was the second most important aspect of non-clinical quality of care in all of the countries.

All this suggests that dignity is more than a mere nicety in care - it is in fact a central element in the provision of high quality care.”

Dignity and Older Europeans

- 3 years cross-national comparative qualitative study, funded by the European Commission Fifth Framework Quality of Life Programme
- Partnership between nurses, philosophers, sociologists, psychologists, clinicians, health service researchers, NGO's.
- Involved 6 countries: the UK, France, Ireland, Spain, Slovakia and Sweden

Slide 2

It was these considerations, which led to the interdisciplinary project funded by the European Commission between 2002 and 2005 and which I was privileged to lead. A theoretical model of dignity was developed and its relevance to the experience of dignity in the lives of older people was examined from the perspectives of older people themselves, health and social care professionals and young and middle-aged adults in the United Kingdom and five other European countries.

Focus group participants

- 89 focus group involving 391 older people
- 85 focus groups involving 424 professionals
- 89 focus groups involving 505 young and middle aged adults

Slide 3

In total, 265 focus groups involved 391 older people, 424 health and social care professionals and 505 adult participants from younger and middle-aged groups.

The results showed that Dignity was a multi-dimensional concept, which was meaningful and salient for older people. The project explored all aspects of dignity in the lives of older people and before exploring dignity in health and social care it is worth mentioning the broader context which impacts on dignity in care.

Dignity in care in context

- Ageism
- Undervaluing and fear of old age
- Cultural context of old age
- Society needs to embrace a broader notion of the dignity of old age

Slide 4

Very broadly, dignity in care is part and parcel of the wider context of dignity as a whole. Although there are many good reasons to focus on dignity in care not least because older adults are at their most vulnerable when they are in care situations, the sense or experience of dignity depends on factors not related to care, such as ageism in our societies, cultures that undervalue or fear old age, lack of societal respect resulting in old age being a subject of ridicule rather than of celebration, and these all need to be addressed before we can be totally optimistic that dignity will be ensured in the care context.

What older adults said:

“ They (care staff) never make me feel just like another old woman. They remember who I am, a mother, a grandmother, that I bring another life with me. “

Slide 5

Dignity is essentially about treating people as individuals.

It can mean different things to different people and possibly different things to the same person at different stages of their lives. Individuals change and so does the social context in which we live so that what is acceptable and convention at one point may be unacceptable at another. This means that flexible person-centred care – often talked about but not always delivered – must remain a central tenet of dignity in care.

This participant exemplifies such notions when she states that the

care staff never make her feel just like another old woman. They remember who she is, the important roles she plays and that she brings a personal history and identity with her.

What older adults said:

There is another kind of not respecting dignity, that isn't as severe, like laughing at someone when they've said the wrong word, because when we get older we might drift from one subject to another.”

Slide 6

The literature on dignity tends to concentrate on physical care which is of course fundamentally important, If someone is hungry, dirty or in

pain they will not have a sense of dignity - but if their physical needs are taken care of while their emotional, psychological or spiritual needs are overlooked, dignity will not be possible.

This is what older adults had to say about being ridiculed or ignored which greatly impacted on their self-esteem and dignity.

COMMUNICATION:

Slide 7

The right kind of communication engenders respect and poor communication such as ignoring people or speaking down to them, making them feel a nuisance, makes people feel unworthy reducing them to a child-like state.

Ageism may well be at the heart of poor communication but there are other causes. Hard pressed staff are often aware they aren't taking time to communicate and many would like to have the time to do it better. Domiciliary carers visiting people in their homes sometimes have as little as 15 minutes to perform their duties. Task orientation also detracts from effective communication. Time needs to be built in to services to enable adequate communication and reduce isolation and people should be communicated with respectfully as equals. Better education and training preferably involving older adults themselves could make a significant impact on standards of communication.

What older adults said:

- “ I went into this particular specialist and instead of talking to me, he was writing all the time. I could have been an elephant! He said to the nurse “ Take her in there and her to strip down” and I just said: “ Am I invisible? “
- “The nurse and doctor just chatted together while he put in the drip - it was awful. They just moved him as though he was an object. Not one word, not a smile - nothing.”

Slide 8

But there can be no excuse for talking over people's heads in a way that excludes or ignores the person as this reduces people to objects and denies dignity.

These participants describe the humiliation of being ignored during everyday practices. Virtually all participants decried the routine use of first or pet names rather than being called by their title and surname, as this reduced older people to the status of children and made them feel patronised.

PRIVACY

Slide 9

Privacy is closely allied to dignity and older adults often expressed concerns about this aspect of care. Privacy concerns having space to conduct one's business in private as well as the more obvious protection of modesty during intimate care. However lack of privacy is all too evident in health and social care settings.

What older adults said:

- “ I felt very embarrassed on the hoist and I used to say “ Can I cover myself up” and they just pulled your night-dress down over your knees, but the back view was wide open to anybody. Also it was often the male nurse who would help you and I was so embarrassed about that.”
- “ You can hear everything that is going on behind the curtains. The staff shout as if you are deaf or stupid, saying things like “ I am going to stand you up now and do your bottom as if they have to explain everything, and that means that people right next door can all hear. Or when they come round asking “ Have you opened your bowels today”. There's not much dignity then.

Slide 10

Older participants complained about the use of hoists for lifting resulting in a lack of modesty; flimsy curtains separating beds, which staff pop into and out of when intimate care is taking place or shouting out intimate details so that others can hear.

CONTROL AND RISK TAKING

Slide 11

Older adults want to feel in control over their lives but they acknowledged that this is easily lost during periods of illness and increased dependence.

Risk aversion was also decried by participants who wanted support for independent living rather than risk free lives – These are people with many years of experience of taking risks, and as evidenced by their age, succeeding. Being put to bed at 6 pm because that is when the carers can visit is not dignified care. Fear of losing services means that older adults feel unable to challenge care providers when they feel they are subjected to unnecessary paternalism - preventing someone from making their own tea and toast may tick all the health and safety boxes but does little for their dignity.

Even kindly care can strip away one's sense of control. Often care decisions are made without the individual's participation even down to where their future home will be.

Care must be person-centred rather than process driven if it is to instil a sense of self worth.

FOOD AND NUTRITION

Slide 12

Food is essential for life, but it is also much more. For most people eating brings pleasure as a social activity. Having a choice about what to eat and drink, when to eat it, whom to eat with are things we take for granted. Older adults in hospitals or nursing homes are highly dependent on others for all aspects of their nutrition. However in situations of dependence many older adults face lack of choice, lack of special equipment, using plastic bibs like babies, rather than napkins which all deny dignity.

What older adults said:

- “They mashed her tables up in part of her dinner like they do to the dog you know I mean that, that's not on is it? It's just not on. That's the most undignified thing I've ever seen.
- “They would bring round the food and place it at the bottom of the bed. Then someone else would come along and take it away untouched. If we hadn't gone in there to feed my father he would have died of starvation. One of us went there every meal time.”

Slide 13

Many described poor practices and lack of assistance so that relatives had to take responsibility for ensuring adequate nutrition. Such concerns are also evidenced in the research literature, which highlights the numbers of older adults experiencing malnutrition in health and social care.

USING THE TOILET IN PRIVATE

Slide 14

Concerns about use of the toilet gave rise to many complaints and both dignity and human rights are undermined in relation to this basic need.

What older adults said:

- "I've seen caregivers who didn't treat certain people in a dignified manner. Once one came in with a list to check who had to go to the toilet. People don't go to the toilet by list. They have to go when they need to. Someone asked the nurse to take them. She looked at the list and said "It's not your turn." How do you like that? Does that person have dignity or not? That's not treating someone with dignity."
- "And you see again at night, they're short staffed and she was told, "Wet the bed, it's easier to change the bed than get the hoist."

Slide 15

Inadequate bathrooms, mixed –sex toilet facilities, being forced to use commodes at the bedside, failure of staff to respond to requests to use the toilet, pressure to use incontinence pads, block treatments and inadequate hygiene facilities all deny dignity.

DEATH WITH DIGNITY

- "I remember when my husband died, he was a very proud man and they knew he was going to die that night. A nurse came in, a real hard sort of nurse and my friend said, "Can we wash him and put him into his clean pyjamas? She said "Oh don't put him in clean pyjamas, he is not going to be here much longer." I said to the nurse "It's his dignity, I want him washed and changed." That's dying with dignity isn't it?

Slide 16

Finally the lack of dignity at the end of life was another concern mentioned by older adults.

DIGNITY MATTERS BECAUSE..

- When human dignity is lost or denied, people "give up" and are more likely to become dependent requiring even more costly provision.

Slide 17

Issues of dignity are serious human rights issues.

Rights to freedom, to respect for dignity, to be treated with equality and fairness, the right not to be humiliated or subjected to degrading treatment, are too important to be left to chance. When human dignity is lost or denied, people 'give up' and are more likely to become dependent requiring even more costly care provision. It is clear that for many frail and vulnerable older people their dignity and human rights are violated on a daily and systematic basis.

My answer to why is this so is that the current emphasis on autonomy and independence in policy and service delivery for frail older people brings with it inherent risks, which can have far reaching consequences.

VALUING FRAIL OLDER PEOPLE

- "If you're demented, you're wasting people's lives - your family's lives - and you're wasting the resources of the National Health Service."
- "I think that's the way the future will go..you'd be licensing people to put others down. Actually I think why not, because the real person has gone already and all that's left is just the body..."

(Warnock M. A duty to die? Life and Work. October 2008, 23-25)

Slide 18

For example, recently, Baroness Warnock, the UK government adviser and moral philosopher, argued that people with dementia had a duty to die. She stated that "If you're demented, you're wasting people's lives - your family's lives - and you're wasting the resources of the National

Health Service". For Warnock there is "nothing wrong" with people being helped to die for the sake of their loved ones and society. She went on to highlight her vision for the future - that people would "be licensed to put others down" because "the person has already gone and all that's left is the body...".

We need to be aware that autonomy is A moral good not THE moral good. It is one value not THE value and it has limits especially for patients who are, no longer autonomous or who are totally dependent on others for their care.

People who have lost some capacities are still human beings with identities, people who are still worthy of our care and however much we cling to autonomy and independence, the reality for frail older people (who of course are not all older people) is that they do become more dependent physically and mentally so that care givers must provide increasingly extensive care. But we should not value those lives any less.

FOCUS ON DIGNITY

- Violations of the dignity for frail older people can best be removed by focusing on dignity rather than emphasising autonomy and independence.
- The focus on autonomy and independence can lead to the frailest and most vulnerable older people being viewed as minimal human beings and/or failures.
- Ensuring dignity protects all interests and demands a greater moral force even when all autonomy is lost.

Slide 19

If we fail to acknowledge that despite our failing capacities, we are all worthy of care this will lead to some people being viewed as 'minimal human beings' requiring only 'minimal moral consideration' as evidenced by Warnock's comments.

When we focus solely on considerations of autonomy this assumes that the highest good is to maintain independence, and that dependence is a harm resulting in automatic failure for both the person and those providing care as autonomy & independence can't be restored.

Decent, dignified care for frail older people often requires beneficent paternalism in ever increasing degrees as physical and mental functions deteriorate. And although this means we need to be extremely alert to the potential for abuse, it is the moral character of the care givers rather than a weak notion of patient autonomy that should be the basis of our actions.

Even the frailest or most severely demented person still has moral worth despite being incapable of exercising any autonomy. And, although it may not always be possible to promote autonomy, it is always possible to give care that enhances dignity. Indeed, we can violate a person's dignity if we set unrealistic goals in relation to autonomy. When the dignity of frail older people is given centre stage this protects all of their interests.

The negative view of long term care was echoed frequently by participants in the DOE study, who saw it as being as repressive and invasive - a place where one waits to die. Without financial, material and human resources to ensure the highest standards of care this will not change and unfortunately in the current economic climate it is unlikely to do so.

But even if all the resources we could imagine were available, attitudes to the care of frail older people will probably remain if autonomy and independence are hailed as the ultimate goods.

It is then little wonder that caregiving for frail and dependent older people is seen as inferior to that for younger or acutely ill members of society and this fact impacts greatly on the professionals' sense of dignity.

CONCLUSION

- Focusing on dignity can restore the personal dignity of care-givers by recognising the inherent value of caring.
- Respect for the human dignity of frail and / or severely demented older people satisfies their basic human rights, demonstrates our care and concern as a society and enhances our own dignity.

Slide 20

By focusing on dignity we would have to consider the dignity of the carer, be they professional or lay, and caring itself would acquire a greater moral value, as its intrinsic worth would be more readily apparent.

Ultimately, it is respect for individual dignity that demonstrates our care and concern for frail older people and it is this response to their inherent moral worth that enhances and expresses our own dignity.

Human beings are more than just sharp minds and critical thinkers, it is care and respect for the whole person, not just their capacities, their reason and their memory, that should form the basis of any satisfactory ethic of older people's care.

FINALY

"Whether by stroke, by Alzheimer's, by poverty or by whatever cause, we stand at risk of losing everything achieved over a lifetime. Each of us, however, dimly, carries this unspoken awareness during our lives. Life can end badly: fear of aging is still rooted in this grim understanding. Dignity in old age matters because every one of us carries this sense of vulnerability and because we fear becoming less than ourselves in the last of life.

(Moody, 1998)

Slide 21

Finally I leave you with the words of Harry Moody who offers each of us prudential reasons for promoting dignity in old age because we are all equally vulnerable.

How we care for dependent older people will test whether modern life has not only made things better for us, but also whether it has made us better human beings.

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3.3 Workshop:

ADDRESSING THE ACADEMY: COMPLEX APPROACHES IN GERIATRIC AND GERONTOLOGICAL EDUCATION TO AND SUPPORT OF FRAIL ELDERLY PEOPLE

Key question: Geriatric and gerontological education why?

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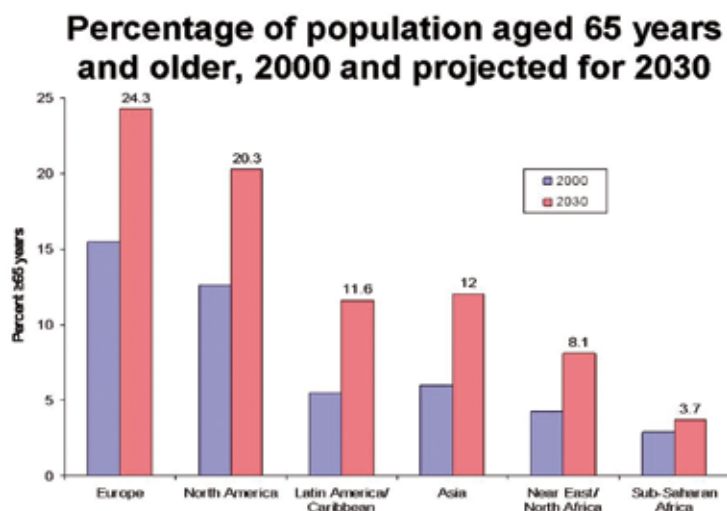
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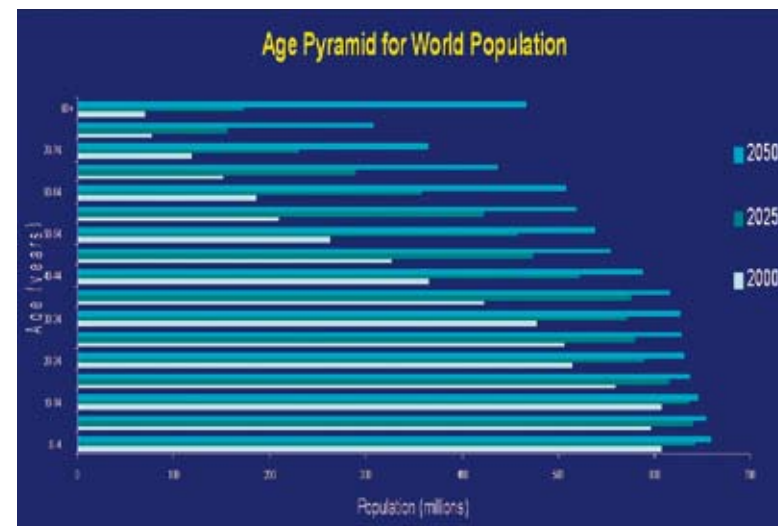
“Developing Ageing Research and Teaching in Europe“

One third of the population of Europe will be over 60 by the year 2050. However, we do not need the extrapolation of figures to 2050 to justify the urgent imperative to improve education on ageing in Europe. In terms of demography, Europe is already being described as the oldest continent in the world.



This has unfortunately led to the emergence of negative stereotyping of old age and ageing. Ageing in Europe is now often described in the media as a ‘demographic time bomb’.

Such negative thinking can be pervasive in society and can influence policies in many aspects of life including health, education and social welfare. It is therefore important to emphasise that most people over 60 are healthy and wish to continue to play an active role in society. Educational programmes on ageing must be set against this background.



However, having acknowledged this, one must also take into account that the numbers of old old (80 and over) are also rising and that it is largely this group which will need most support from health and social welfare services because of cumulative disability, frailty and vulnerability in the last years of their lives. It is increasingly realised that current education in medicine and related disciplines do not provide the knowledge and skills that are necessary to manage chronic disability and frailty in older people.

EDUCATION ON AGEING IN EUROPE

Although education on ageing is obviously an area which needs rapid development across Europe, there is a dearth of publications in the medical and scientific literature on the subject. One of the more recent studies on undergraduate teaching in geriatric medicine was carried out by a team based in the University of Perugia (Cherubini et al 2006). They point out that undergraduate geriatric medical education remains a major area for development across Europe. They found well estab-

lished programmes in some countries which included Scandinavia, the United Kingdom, Belgium and France. These programmes varied greatly in terms of quality and length. Teaching in geriatric medicine is mandatory in Spain but only one medical school in the country has a professor of geriatric medicine. In many of the other European countries teaching in geriatric medicine is not mandatory and is still at an early stage of development. Few countries had teaching programmes which were well integrated with the medical curriculum. Some countries such as France and the United Kingdom have professorships or academic departments in geriatric medicine in most medical schools. Unfortunately at least seven of the medical schools in England which previously had academic departments in geriatric medicine no longer have professorial appointments in the subject. Some of this decline may be attributed to the emphasis placed on research output and income in English Universities, with a resultant investment in academic areas which are perceived to attract large research grants. Another report undertaken as a collaborative initiative of the W.H.O. and the International Federation of Medical Students Association and published in 2002 found great gaps in structured teaching on ageing and older people in countries right across Europe (Keller et al 2002).

One of the significant factors for this lack of development appears to be the failure to recognise geriatric medicine as a distinct specialty in a number of European countries. There is also an insufficient number of academic geriatricians. Studies have shown that medical students without formal teaching in geriatric medicine develop negative attitudes to older patients as they progress through medical school. In contrast well structured programmes particularly in the early years promote positive attitudes.

TEACHING ACROSS DISCIPLINES

Family doctors should have a firm grounding in geriatric medicine as they are responsible for the day to day healthcare of most older people. A variety of specialists treat older people referred to hospital. Some specialties such as orthopaedics, urology and vascular surgery deal largely with elderly patients. It is therefore important that all medical students receive teaching in the health care of old age.



[Multidisciplinary teaching] It is equally important that students in all other disciplines within health sciences should also be exposed to teaching on ageing and on the care of older people.

Many reasons have been found for delaying the introduction of geriatric medicine into the undergraduate teaching curriculum of some medical schools and universities. Reasons put forward include lack of space in the teaching programmes or scarcity of qualified teachers and training venues. Such excuses are often a manifestation of negative attitudes and an ageist agenda. Where there is a will there is usually a way. The emergence and cultivation of young staff, with vision and determination, have been one of the most effective ways to bring about change in universities and their teaching hospitals.

CHANGES IN CURRICULUM

The structure of medical school training has changed dramatically in many European countries over the past decade. Emphasis has moved away from didactic lectures to smaller interactive groups with the aim of stimulating an enquiring approach to prepare students for a lifetime of learning and self education. Basic science and clinical teaching have been integrated and there has been a greater emphasis on inter-disciplinary and community-based courses.

The teaching of geriatric medicine is an ideal way of promoting the reforms outlined above. The presentation of illness in older people is gen-

erally complex making it very suitable for small group discussion and analysis. Students can also be taught in an inter-disciplinary environment making it easier for them to work in multi-disciplinary teams later in their professional careers. Most modern geriatric departments are developing or already have developed community outreach services which facilitate interaction with older persons in their own homes.

BLUEPRINTS FOR TEACHING

Over the years a number of documents and papers have been developed which offer blueprints for the establishment of academic teaching in geriatric medicine both on a national and European level. They all agree that courses in geriatric medicine should form a core element of the curriculum and they have clearly annunciated objectives in terms of knowledge, skills and attitudes. Good academic departments provide models which may be copied by others and it is essential to encourage the development of such units. A successful department will act as a catalyst to develop significant initiatives in other disciplines. The hallmarks of a good department include strengths in three areas – clinical practice, research and teaching.

THE IMPORTANCE OF RESEARCH

Geriatric medicine is ideal for translational research bringing advances from the bench to the bedside and from the bench to the home. High quality teaching will emerge in departments which have solid foundations in clinical practice and research. Some believe that it is difficult to develop first class research in departments of geriatric medicine with modest resources. However, one should take a more positive and optimistic approach. The drive to encourage healthy ageing and to decrease disability from disease is channelling significantly more funding into ageing research. This is apparent by the increased emphasis on ageing in both European, national, and philanthropic research agencies. Increased research funding gives departments more opportunities in the scope and structure of their teaching programmes at both undergraduate and post-graduate levels. It will also enhance the teaching capacity and teaching profiles of the departments.

SIGNIFICANCE OF A STRATEGIC PLAN

The development of an academic department of geriatric medicine is rarely an easy undertaking and one must be strategically prepared to optimise opportunities for developments. The preparation of a document or strategic plan outlining the vision of the department and its potential can prove to be of great value. This certainly was our experience in Trinity College, Dublin. The plan should look at the academic opportunities both in teaching and research which exist in the hospital and university. The document could form the basis of discussions with those in positions of influence and power in the hospital, health board, university and government departments. In our case we developed a strategic plan with the vision of creating a Centre of Excellence which would embrace health care, research and teaching and which would form strong links with the local community. The documents did not yield immediate results but proved a great advantage when after unforeseen but significant opportunities for development presented later.



[Mercer's Logo] These opportunities have enabled us to establish a research institute, The Mercer's Institute for Research on Ageing and to expand the numbers of our senior academic, clinical and research staff. This in turn has impacted on our ability to develop a more comprehensive teaching programme on a multi-disciplinary basis.

It also stimulated an interesting parallel development, the formation of a group known as the Trinity Ageing Consortium. This brought together individuals interested in ageing right across the University, encouraging collaboration in a number of areas and raising the profile of ageing both within the University and nationally.

CONCLUSION

To conclude I have discussed the demographic imperative which demands that European universities should focus more on ageing and older people. This can be argued purely on the basis of social responsibility. However, a serious engagement in the field of ageing studies can greatly enhance the research and teaching profile of European academic institutions in technology, science, health sciences and the arts with the obvious social and economic benefits which would flow from such an engagement.

Ariela Lowenstein [IL]

“Developing an Interdisciplinary Innovative Masters Program in Gerontology”

The purpose of this presentation is to describe the goals, development and outcomes of an innovative interdisciplinary Masters Department of Gerontology, one of two programs in Israel. The initiation and development of the Department was in response to the challenges facing the Israeli society regarding the rapid aging of the population, and an accelerated growth of welfare and health services for the aged. This was combined with a growing body of research in gerontology and geriatrics and a lack of specific and focused teaching and training frameworks, mainly at the Masters level. The development of the service network, especially during the last decade, caused a shortage of human capital trained in gerontology, at the academic and research fronts, and also in top administrative and care roles. Thus, high quality graduate education was needed. Key program components reflecting the innovative nature of the program activated at the Masters Department of Gerontology will be described based on: (a) Level of development and promotion of knowledge; (b) Goals; (c) Influence, and (d) Patronage. The outcomes of the program which is in its 10th year show an interdisciplinary faculty and student body both of whom report high satisfaction level, involvement, and obtaining wide knowledge bases in gerontology and geriatrics. The number of candidates applying increases each year. A new unique program for physicians had evolved, with strong support from the University of Haifa, the Council for Higher Education in Israel and key service organizations for the elderly. The implications are that such a program enhances the level of professional leadership in the field of aging, and

expands the cadre of academic faculty. Many of the graduate advanced to key positions in their workplace and several finished their doctorate degrees either in Israel or abroad.

Josef Hörll [AT]

“Paradoxical effects of legal guardianship – the Austrian experience”

In Austria, the number of old people with a guardian has been rising rapidly over the last decades. Today, more than 60,000 persons are living under guardianship. Each year about 7,000 to 8,000 new cases are added. Should the hitherto existing trend continue it seems not completely unrealistic to expect one per cent of the whole population to be under legal guardianship in the not so distant future. In sheet no. 1 you can see the increase in the number of guardianship matters dealt with by the family courts. These are not prevalence figures but the total number of cases submitted to the courts. Nevertheless, the dynamics in the development is clearly illustrated. Despite some adjustments to limit the growing demand, the upward trend continues as reported at the yearly conference of the Association of family judges held just three weeks ago. The “success” of this legal instrument is rather unwelcomed. Before I elaborate a little more in detail on the resulting problems of quality assurance and of loss of personal autonomy and freedom, and on the factors that can be identified to attribute to this development, let me sketch very briefly and in a simplified way the basic procedures in the application for legal guardianship.

How does guardianship come about and what is the procedure like in court? The district court having jurisdiction may appoint a guardian at the request of the person concerned or at the suggestion of a third party who takes the initiative. Usually, the suggestion to open guardianship proceedings comes from a relative, an authority or a social service. The contact to turn to is the judge in charge of guardianship cases at the district court which has jurisdiction over the place of residence of the person concerned. The judge will first talk to the person concerned, and only when the judge comes to the conclusion that a formal procedure will make sense, she or he will open the case formally. Then the court will name an expert to draw up a medical opinion. Simultaneously, a provisional guardian will be appointed. At the end of proceedings, the person

concerned, the medical expert and the provisional guardian are heard in court. The medical opinion is discussed, the provisional guardian gives a report and the person concerned gives his or her point of view, if possible. Finally, the judge issues an order stating if a guardian is appointed, and if so, who it is and which specific matters he or she has to attend to. Guardianship is not intended to be a life long measure but in reality it is in most cases. The tasks of a guardian as a legal representative are determined by the judge on a case-by-case basis. However, the guardian invariably has to arrange for the care the vulnerable person needs and to be in touch with him or her at least once a month. The person under guardianship does not have the legal capacity in these matters that the guardian is in charge of. This means that he or she is unable to enter into contracts, file petitions or take any other legal action within the scope of responsibility of the guardian. In all other respects he or she continues to have legal capacity and responsibility. Who can be a guardian? As you can see in sheet no. 2, most guardians (around 70%) are persons who are close to the person concerned (next of kin, friends, acquaintances), followed by attorneys-at-law, notaries or other persons who are suited to the tasks. Non-profit advocacy organisations will be appointed as guardians if no person close to the vulnerable person is available and/or if special requirements are linked with the guardianship. Normally, the professional background of guardians from non-profit organisations is social workers, psychologists or lawyers. They can be employed staff or volunteers. They undergo internal training when entering the organisation and further continuing education and supervision is provided by the organisation. Regular team meetings in order to discuss work are mandatory. However, the fact of the quantitative expansion leads to severe problems of quality assurance. There are not enough professionally educated guardians available and there are not enough funds to finance them. Attorneys-at-law or notaries will be appointed as guardians if the matters to be attended to are mostly legal in nature and/or if no person close to the person or an advocacy organisation are available. Attorneys-at-law and notaries may not take on more than 25 guardianships. Other appropriate persons (e.g. social workers) may be appointed if neither persons close to the person concerned nor an advocacy organization nor an attorney or a notary is available. These persons are not allowed to assume more than five guardianships. Ethical questions arise. It is no special secret that lawyers are basically motivated by monetary considerations. Normally, they lack any geriatric or psychiatric knowledge.

Apart from that, it goes without saying that you cannot provide effective professional assistance for 25 incapacitated people. I can say from my own experience that attorneys or notaries prefer to keep contact by sending letters. This is quite strange considering the mental problems of many persons under guardianship.

The appointment of family members is sometimes also a dubious solution because they may have strong vested interests especially in financial matters. To a certain extent the endeavour to "counteract" social problems of old age and care needs with the help of legal procedures is contradicting itself. I come to my second point: What structural factors may be responsible for the explosion in guardianships? A first and seemingly apparent explanation may be found in the growth of the target population, i.e. an increase in the number of vulnerable persons, especially elderly persons. To say it quite clearly beforehand, there is no evidence that the process of demographic ageing is a major factor for this development. There is no doubt (see sheet no. 3) that the old and very old, especially people in their 80s and above, are grossly over-represented in guardianships. Persons aged 80 years and over constitute only 4% of the total Austrian population but no less than 37% of all persons under guardianships, and persons aged 70 to 79 years make up 8% of the total population but 20% of the population under guardianship. The incidence figures of old and very old persons who are granted guardianship today is roughly ten times as large when compared to the situation 20 years ago. In the same time interval the growth factor for persons 80+ is only 1.5, i.e. much lower. Similarly, the much-discussed increase in Alzheimer's disease and other forms of dementia makes only a relatively small contribution; the number of demented elderly is about three times as high as compared to the situation 20 years ago. Certainly, this increase is massive, but not massive enough to explain that the number of persons under guardianship, which is about seven times as high as could be expected on the basis of demographic and epidemiological figures only. Still, dementia is diagnosed in almost 40% of all cases among all age groups taken together. We know that this illness has many stages and faces; nevertheless, the diagnosis of dementia obviously leads rather quickly to guardianship. But there must be additional factors. To explore this fact further we may refer to the fact that everyday life is much more complex today for everybody, i.e. one has to deal more often with rather complicated legal or practical matters. Consider only such technological innovations such as automated bank

services, etc. Thus, there can be little doubt that life has become more complicated in many respects: as a rough indicator let's have a look at the development in the number of law-related professions. Between the mid-80s and today in Austria we can observe a doubling in the number of professionals in the legal field, lawyers, consultants, etc. As true this is, again, the growth in the number of guardianships is much, much higher than, for example, the growth of legal matters. A third explanation may point to allegedly dwindling family resources and the resulting social isolation of vulnerable elderly persons who cannot handle legal or even everyday matters on their own and have to refer to specialists outside. Up to now, however, this popular view cannot be upheld towards scientific evidence. The vast majority of elderly persons even in their 80s is still well-integrated into family networks and – overlooking the development in the last 20 to 25 years – there is not much difference to be noticed in the number of children, in contact frequencies with family members etc. since now and then. The expected negative effects of increased childlessness etc. will have an impact – if at all – for the elderly population only in the future. Furthermore, no massive increase in the number of institutionalized elderly persons can be observed; it is completely true, however, that the percentage of persons under guardianship is dramatically higher in institutions (in some nursing homes up to 70% of persons are under guardianship!). It is also true that being single or divorced and/or living alone in an one-person-household is a major risk factor for being under guardianship. These are rather compelling indicators that legal assistance is needed most by people who are not integrated into family systems. Nevertheless, I have to repeat and underline that there is no convincing evidence that social isolation among the elderly has dramatically increased since the 1980s. Consequently, the increase in guardianships cannot be attributed to the alleged worsening of family integration. The third and fourth explanations for the massive increase in guardianships come even closer to the nucleus of the problem, even when the indicators available are rather indirect. To begin with, there is a distinctive trend in society toward formalisation and bureaucratisation. Looking at the initiators for guardianship we notice that the origin of half of all guardianship initiatives can be traced back directly to institutions (e.g. homes for the elderly) and a further 20% are initiated by relatives who are more or less pressed by way of “advice” and counselling from institutions. It is in the very nature of bureaucratic organisations to seek unequivocal transparency in rules

and procedures and they consequently demand a competent person vis-à-vis to deal with.

In my eyes the arising paradox is as follows: while it is certainly positive and a pillar of the constitutional state to have strict and reliable legal proceedings and certain bureaucratic stipulations because they serve to protect vulnerable persons – at the same time these stipulations may easily overburden beneficiaries. There is no doubt that informal solidarity and informal problem solving are sometimes prone to abuse but at least they do not need guardianship regulations. Freedom and autonomy are taken away often at a relatively early stage of disorientation to make place for formal bureaucratic so-to-say water-proof regulations. Of course, the family judges can deny the appointment of a guardian but they do so very rarely.

The experts tend to opine in favour of guardianship (to be on the safe side) and the judges tend to follow the experts' advice, especially when very old and possibly demented applicants are involved. This brings me to the fourth and last argument to explain the increase in the number of guardianships. This refers to the ongoing differentiation of welfare claims. What concrete problems do arise in connection with guardianship matters? Primarily, it concerns everyday financial management, but also problems of care and medical treatment in institutions, admissions to institutions of long-term care, insurance matters etc. To illustrate this point I want to present a final example, taken from the Austrian social welfare legislation regarding the attendance allowance. The attendance allowance is granted with regard to the actual need for care and with no regard to the reason for the disability.

This provision should enable a person with a disability to live in his or her familiar surroundings at home. Better conditions for help and care within the family as well as increasing the number of professional carers are objectives of this provision. It is a contribution to the costs of help and care. I cannot go into the details of provisions and the assessment procedures involved. It is essential, however, to emphasize that the Austrian kind of attendance allowance is basically a consumer-directed programme. That means that the allowance is linked to a transfer of responsibility to the beneficiaries and they are autonomous in their decisions. At least for persons classified at lower impairment levels there is no need to furnish proof of whether or how the means have been consumed. Complex problems of assessment have emerged. Direct payments are to be

made only to those elderly who are of sound mind and can handle their own finances. But the question is: What kind of mental disability should disqualify elderly people from managing their allowances on their own? Should it be only severe cases of dementia, or also cases of emotional disorder and depression?

There is some evidence from research. I want to restrict my remarks to elderly recipients having children, living in private households alone or in shared households. As far as the reality of their family life is concerned, it seems reasonable to assume – and this assumption is supported by research results – that most children will help their care-dependent parents with administrative tasks. In fact, joint budgets are kept in more than a quarter of cases; such budget sharing almost certainly implies that the children are the ones to make decisions and it is somehow logical to formally authorize them to do so. No detailed data on private budgets is available, so we have only scarce information on how the cash benefits are actually spent. All the same, it seems to be rather evident that benefits are quite often passed along to informal caregivers or are contributed to household budgets. This is in accordance with the apparent (if not explicit) intention of the lawmakers that family carers should be remunerated this way. A certain amount is used for the purchase of formal services. Of course, people with cognitive impairment need even more support in managing services, if they are in a position to make decisions at all. Consequently, the family carer takes over the role of the surrogate decision-maker in most cases.

As another indicative detail it should be mentioned that more than half of all interviews in a particular research study with old persons receiving attendance allowances were conducted as proxy interviews because the old respondent was not ready or able to answer questions. If the elderly are deprived of giving interviews isn't it to be expected that they are quite easily deprived of their legal capacity, too? Thus, my final conclusion can be summarized in one sentence: to achieve exactness and accuracy in the everyday life of the elderly we have to live with the paradoxical effect of diminishing the autonomy of an ever-increasing portion of the elderly population.

Bridget Penhale [UK]

“The use of guardianship of older people who lack mental capacity”

BACKGROUND AND INTRODUCTION

Thank-you very much for inviting me to this conference in the beautiful city of Prague; it gives me great pleasure to be here. As there is only a little time for us to make our presentations I will try to be as brief as possible and will commence straight away.

By way of introduction, it is necessary to acknowledge first of all that in many countries, there has been long-standing concern about the possible needs for protection by individuals who lack the ability to take decisions for themselves or to be responsible for their own health, welfare and well being. In a number of countries, in recent decades we have seen the development of legislation relating to this area, including provisions for guardianship of the individual. There are a number of reasons for such developments. These include issues relating to demography and the ageing of the population and concerns about increasing numbers of older people (in particular) who are affected by conditions that result in cognitive impairment in later life. The move towards de-institutionalisation and community care (people remaining living at home in the community for as long as possible and practicable) has also had an influence here and it is perhaps not surprising that in view of such issues there has been a rise in concern about matters relating to decision-making and incapacity and what happens when an individual cannot take decisions for themselves (whether this has occurred since birth or has happened at some later point in the life-course).

ISSUES IN GUARDIANSHIP

When considering guardianship and its possible uses, it is noticeable that there are a number of issues that arise in relation to this. For example, there are apparent tensions between issues of autonomy and independence and those of safety and protection. It is probable that individuals would prefer to be independent and self-determining as far as (and for as long as) possible, even if that means that risks to personal safety are involved. In addition, there are ethical issues relating to control, use of force, coercion and/or intimidation of individuals. The use of guardianship for adult mental health ‘problems’ is also a rather contentious area (although in my country this is one of the most common and

central uses of guardianship) and evidently there are issues relating to advocacy and rights (human, civil and citizenship), which may need to be considered here. Furthermore, the role of the state in guardianship may require some examination. For example, is the primary role that of 'parens patriae' (father for the country) or 'in loco parentis' (in place of the (natural) parents)?

USES OF GUARDIANSHIP

If we consider examples from countries where such provisions exist, a number of possible uses of guardianship can be found. These include decisions about such things as where a person should live and whom they should live with, attendance requirements (for example, for work or clinic/hospital related appointments), and health and welfare provisions. Decisions about use of finances and affairs relating to property may also be included. It is also possible to find some examples in certain countries where guardianship is explicitly used for the provision of protection, assistance and support for individuals. This would include the possibility of protection from abuse, neglect and/or exploitation.

GENERAL PRINCIPLES

There are a number of general or guiding principles that should operate within any system of guardianship that is developed. These include the following elements:

- All adults are entitled to live in the manner they wish to and to accept or refuse support, assistance or protection as long as they do not harm others and they are capable of making (their own) decisions about these matters
- Every adult is presumed to be capable of making (their own) decisions about health and personal care and financial affairs, unless proven otherwise
- All adults should receive the most effective but least intrusive and restrictive form(s) of support, assistance or protection when they are unable to care for themselves or their financial affairs
- Alternatives such as the provision of support and assistance must have been tried or carefully considered before any court intervention is undertaken

- An adult's way of communicating with others is not grounds for deciding that he/she is incapable of making decisions
- On their own, unwise or eccentric decisions by an individual cannot be considered as grounds to consider that the person lacks capacity
- If a person is in an abusive or neglectful situation and can take their own decisions, then they can refuse help and assistance (in some jurisdictions this may be over-ridden if the person is in a very severe or life-threatening situation).

CANADIAN GUARDIANSHIP (BRITISH COLOMBIA)

When preparing this presentation, my attention was drawn to examples from Canada, which has been very forward thinking in recent years in relation to capacity issues. As an example, I would like to show you some of the principles that have been developed and are in place in British Columbia. In that jurisdiction, action may be taken if the situation is urgent, dangerous or cannot be resolved informally and the 'designated agency' (health and community living services) is concerned that the adult cannot get assistance due to either physical restraint or handicap OR illness, disease or injury that affects decision-making. In such cases, legal tools to protect the individual exist and can be used. These include the following possibilities:

- Right of entry and authority to see adult when access is denied
- Short and longer-term restraining orders to keep (alleged) abusers away
- Support and Assistance Order from court to get adult needed support(s), if assessed as mentally incapable of refusing support/help
- I think that these suggestions may be of interest to us when considering possible future developments later in this presentation.

BEST INTERESTS

- In England and Wales the government enacted the Mental Capacity Act in 2005. This law came into effect in 2007. There are 5 general principles within the Act, which relate to acting in the best interests of an individual. These are as follows:
 - Presumption of capacity: any person is presumed to have capacity unless it is established that this is not the case

-A person must not be considered as unable to make a decision unless all practicable steps to assist them to take the decision have been taken without success

-The person must not be treated as unable to make decisions merely because they take/make unwise or eccentric decision(s)

-Any act done or decision taken within the Act must be done or made in person's best interests

-Before any decision is taken, we must consider whether the result could be effectively achieved in a way that is less restrictive of the person's rights or freedom of action, so the principle of least restrictive action is in place here.

In general terms the following principles should also hold when using the Act. The person must be encouraged and supported to participate in the decision-making process to the greatest extent possible. The question of capacity to take decisions should be related to specific decisions (so the assessment of capacity to take a decision must occur for each decision; there should not be any wholesale view that the person is always incapable, or capable of a particular decision or set of decisions). All relevant circumstances relating to the decision need to be identified. As part of this, we need to find out the person's views about the situation and the decision in question. This process includes consideration of:

The person's past and present wishes and feelings

The person's beliefs, attitudes and values

Any other factors the individual would consider important in relation to the decision

Substituted judgment: what the person would have wanted, were it not for their lack of capacity at this time

The need to avoid discrimination of any type

The need to assess whether the person may regain capacity; does their condition fluctuate, can the decision be delayed until the person regains capacity (if this is likely to occur)?

If the decision concerns life-sustaining treatment, do not make assumptions about the person's Quality of Life; consider your own motivation within the situation (there must not be any motivation or desire for the

person's death)

The need to consult with (significant and relevant) others, if practical and as appropriate, including if the person agrees to this

The need to avoid restricting the rights of the individual if possible (principle of the least restrictive action/intervention holds here).

FUTURE POSSIBILITIES

There are a number of possible developments that could occur in the future. This includes the potential to have some form of legislation to protect adults who experience, or are at risk of abuse, neglect and/or exploitation. It is possible that some form of guardianship may be part of such a development and that all settings (home or care facility or public place) would be covered by this. Decisions about whether self-neglect would also be included in this would need to be taken. In addition, consideration needs to be given to whether there is the potential for such legislation to be enacted on a European-wide basis, perhaps to have some sort of legislation concerning the support and assistance of people who lack capacity. We are already seeing the development of initiatives such as a European network concerning the issue of guardianship so we can hope that further developments will continue in future.

Thanks very much for your attention and for listening today. If any of you would like to be in contact with me for further discussion, my details are as follows:

III. NGOs PANEL



THE POSITION AND ROLE OF THE SENIOR CITIZEN'S ORGANIZATIONS (ISSUES CONCERNING OF THE DIGNITY AND FRAILTY) OR "NGO PERSPECTIVES ON THE HUMAN RIGHTS OF OLDER PERSONS"

Key question: Civic responsibility in the protection of the dignity and safety of the elderly

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Elizabeth Mestheneos [AGE/GR], **Irene Hoskins** [IFA/USA], **Lia Daichman** [INPEA/ARG], **Bridget Sleaf** [HAI/UK], **Gordon Lishman** [ACE/UK], **Sibylle Reichert** [AEIP/B], **Gisli Pall Pálsson** [EURAG/ICL]

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NGOs have traditionally been at the front, the center and at the core of the human rights discussion and the protection of various population groups. The protection of the human rights of the people they represent – be that children and youth, women, persons with disabilities, indigenous or ethnic groups, migrants or persons of various racial backgrounds – is reflected in many of their charters, statements of purpose, action plans and other documents. Yet, until now, and in spite of the rapidly growing proportions of persons over 60 within the general population of almost all countries, relatively few NGOs working in the field of population ageing and providing services to older people, explicitly state that their approach to serving their clientele of older people can be summarized by what is commonly called the “rights-based” approach.

Why is that? For one, with the exception of another purely age-related group, ie children and youth, the special needs and concerns of an ageing population cut across all the other categories mentioned above, i.e. women, persons with disabilities, migrants, indigenous persons, race etc. Age can therefore be regarded as yet another jeopardy that challenges the human rights, the dignity and the well being of older people belonging to any of these other categories. The result may be double and triple layers of discrimination. While the majority of older people remain active and healthy well into their later years, vulnerability, frailty and social isolation may accompany the ageing process at various

stages. Moreover, it can occur in any of the above-mentioned population categories with age being the common factor.

It is therefore the responsibility of NGOs in the field of ageing to shed their tunnel vision and take a very broad view of what age means with regard to the enjoyment of all human rights and fundamental freedoms in combination with all the other factors mentioned above. The UN commonly uses the term “mainstreaming” when it speaks of overarching factors, such as gender and race. “Mainstreaming” age and a human rights approach in the consideration of all policies and practices with regard to older people and all the other categories they may belong to is therefore essential if we are to be successful in formulating the kind of policies and programs that will serve our ageing populations. NGOs must play a vital role in this process.

IFA is an NGO with global reach, global membership and general consultative status with the United Nations. Together with its membership, IFA endeavors to promote a better understanding of the ageing process, the contributions older people continue to make to their societies, their needs, as well as the complex interactions of human rights and age-related challenges across various population groups.

Lia Daichman [INPEA/ARG]

1) The position and role of Seniors Citizen's organizations (issues concerning the dignity and frailty)

The International Network for the Prevention of Elder Abuse (INPEA) is an organization, founded in 1997, which is dedicated to the global dissemination of information as part of its commitment to the world-wide prevention of the abuse of older people. INPEA was born of recognition of and a global sense of responsibility to improve the lives of a large number of older persons who suffer worldwide from abuse and neglect. They face discrimination, marginalization and poverty; are essentially invisible members of society and have no political, cultural or social voice. Our Mission statement and Objectives below reflects our collective thinking of the appropriate approach for a “Senior Citizen's or Older Person's organization such as ours to realize our goal.

INPEA'S MISSION

Acknowledging the diversity of culture, background, and life style of the world population, INPEA aims to increase society's ability, through international collaboration, to recognize and respond to the mistreatment of older people in whatever setting it occurs, so that the latter years of life will be free from abuse, neglect and exploitation.

OBJECTIVES:

- To increase public awareness and knowledge of the issue
- To promote education and training of professionals and para-professionals in identification, treatment and prevention
- To further advocacy on behalf of abused and neglected elders
- To stimulate research into the causes, consequences, prevalence, treatment and prevention of elder abuse and neglect.

INPEA's now has representatives in over 60 Nations. It is through them that we seek to work both from the bottom up and top down. Our broad approach empowers older persons through education and participation which allows their voices to be heard and helps shape public policy. Thus, together with older persons themselves, we strive to strengthen individuals, other members of civil society, NGO's and governments, as we build a foundation based on dignity and a “culture of respect” for older persons so that their basic needs may be fully provided for and their human rights protected. The collective efforts of organizations such as INPEA actively promote and support legal and moral concepts such as the current call for a Convention on the Rights of Older Persons. Thus, it is in this manner which the role of NGO's dedicated to the improvement of the lives of Senior Citizens or Older Persons have and will continue to have a major impact.

2) Civic responsibility in the protection of the dignity and safety of the elderly

There is no denying that first it is the primary responsibility of Governments to protect their citizens, especially the most vulnerable (children, women and the elderly). However, individual members of civil society, as well as corporate members, also have a Civic Responsibility to ensure a supportive and protective environment (social, political and natural) for

the overall good of society. In 1995, The UN World Summit for Social Development held as its core message in the Copenhagen Declaration: "Our societies must respond more effectively to the material and spiritual needs of individuals, their families, and the communities in which they live...." The ".... vision of social development is based on human dignity,...equality... and full respect for various... backgrounds of people".

Building upon the Copenhagen concept of a "Society for All", The Second World Assembly on Ageing, held in Madrid, (2WAA 2002), recognized in the Madrid Plan of Action on Ageing, (MIPAA) the global responsibility of society to protect the needs and right of marginalized Older Persons, calling upon us to work "Towards A Society for All Ages". Unfortunately; in the wake of globalization, and urbanization, and in spite of the many advancements of the past century, the world has experienced an erosion of social capital and a weakening of the concept of civil responsibility.

Further, the UN Secretary General's Report in follow up to 2nd WAA, noted a major roadblock to implementation of MIPAA, "older persons constitute one of the most marginalized groups because they continue to be perceived as vulnerable, resource-dependent and non-productive." (A-58-164) Such a stereotype requires individual commitment to change.

The UN Commission on Sustainable Development in 1992 recognized nine sectors of Civil Society as Key major groups; they include Women, NGO's Business, Youth, Scientific Community, and Indigenous People.

Although, Senior Citizen or Older Persons' NGO's, particularly INGO's are still relatively few in number, in the 1980's they began to play a pivotal role in the arena of civic responsibility and elder protection. NGO's helped to break down isolation and gained recognition by Governments becoming known for building trust, and solidarity. (Hasegawa and Yoshihara), Serving both to empower and protect older persons, NGO's dialogue with key stakeholders. They both receive and provide expertise and guidance to support governments who otherwise do not have the resources or knowledge to best protect the older persons within their jurisdictions. NGO's often lead the "call to action" raising societies awareness of older person's needs and rights, creating networks of bonds with and between individual citizens to mobilize on behalf of vulnerable elders. One such example is INPEA's Launch of the World Elder

Abuse Awareness Day, WEAAD, in 2006. As INPEA Recognizes the 4th Global WEAAD we find that such an effort has reached even the single citizen to take a stand or "snorkel" against elder abuse and injustice. Older Persons themselves wearing "Purple" (the elder abuse awareness color), have mobilized marches and celebrations of elders. Academic institutions have undertaken studies and Governments have passed Declarations recognizing Older Persons contributions to society.

However, failing the broad involvement and commitment of individuals themselves, NGO's could not exist, therefore, their accomplishments attest that the spirit of Civil Responsibility is alive but needs to be nurtured by local governments and Inter-Governmental entities such as the United Nations Program on Ageing, if we are to truly achieve "A Society for all Ages.

Sibylle Reichert [AEIP/B]

ELDERLY DIGNITY AND ABUSE – THE APPROACH OF PARITARIAN INSTITUTIONS AND MUTUAL BENEFIT SOCIETIES

"Dignity means that a being has an innate right to respect and ethical treatment"

Paritarian institutions and mutual benefit societies provide for inter alia not for profit long term care insurance and thus have an important role in promoting elderly dignity. Both organisations are based on the value of solidarity. Paritarian institutions and mutual societies have a complementary approach with regard to elderly dignity and abuse and cooperate closely with other public and private institutions in order to prevent abuse of elderly.

Both organisations call for a better coordination of health and social services in order to ensure best care for people in need. In order to avoid elderly abuse, it is important to monitor and support the care givers (formal and informal), provide for possibility of supervision, training and an empowerment of the dependent. Healthcare providers, long term care insurers, psychologists and relevant authorities need to closely work together and report on any suspicion of elderly abuse, ensure a follow-up of the case and prevent further maltreatment.

The members of AEIP and AIM created several initiatives to prevent elderly abuse and promote the dignity of elderly in need of care.

In the beginning of the years 2000 AGIRC-ARRCO, a French member of AEIP active in coordinated retirement schemes has entered a partnership in order to set up a telephone platform organised by professionals and designated to identify situations of maltreatment. Furthermore, in all the institutions for elderly that AGIRC-ARRCO manages, a plan for the good treatment, including the architecture of the structures and the practices of the professionals has been introduced. This translates into special attention to the acoustical, visual, general living environment, the adaptation to sensorial deficits of all establishments, the training of the personnel, partnership for research and action in order to further develop the existing practices. Furthermore there are reflections about intelligent homes and new technologies.

Our German member BKK, makes a lot of efforts with regard to improving the quality of the care in hospitals. Improving the quality helps to respect the dignity of elderly and prevent elderly abuse. It is important to have a holistic approach and include doctors, nurses, psychologists and family and all the stakeholders concerned. Thus, BKK offers trainings for family members and volunteers. The support of family members already starts in the hospital and brings together family and consultants and nurses to discuss the situation of the person in need for care and find the best solution for him/her. Furthermore, the BKK set up a helpline for carers. Such support of carers may prevent abuse at a very early stage.

Another approach is the one about the creation of a care philosophy for Alzheimer patients, developed by Gineste-Marescotti and applied in a geriatric clinic set up and managed by social partners in France. This is a method of care that maintains the relation between the dependent person and the nurse or carer. The objectives of care have to be clearly set; the approach must be a global and multidisciplinary one. Prevention, diagnosis, care, supporting and accompanying the elderly person and his/her family is important. In the hospital it is important to implement integrated care and maintain the autonomy and ensure the return to home. A medical record has to be made, including a record of the autonomy of the person and a social record within 48h. The dignity of the person has to be respected at all times. 2

In Belgium, several associations in Wallonia, Brussels and Flanders are specialized in preventing elderly violence³. They provide for hotlines to listen, to give orientation and accompaniment. At the request of families, they can also intervene at home, in order to mediate. Moreover they

provide for prevention through organizing training sessions for the professional carers or private individuals working with the elderly. These structures are also opened to the authors of the violence who wish to find the keys to modify their behaviour.

Another example for the safeguarding of the dignity of elderly persons is the Charta of the Rights of People in the Need of Long Term Care and Assistance developed in Germany by the Ministry of Family, Elderly, Women and Youth, the former Ministry of Social Affairs and Health and experts from different levels of long term care (German Länder, municipalities, institutions, senior citizen organisations, long term care insurers etc.). The aim of the Charta is to strengthen the role and the legal status of people in need of long term care and assistance, in summarizing the basic and evident rights of those people. The rights are based on human dignity and are anchored in different national and international legal texts. The Charta formulates quality standards and objectives to be achieved in good care.⁴

These examples will be presented in detail during the presentation.

Gisli Pall Pálsson [EURAG/ICL]

EURAG's philosophy and actions are based on the fundamental principle of human dignity as the ethical basis of European democratic society to be enjoyed by all people at any time in their life. EURAG considers that independence, seen as the right to lead a self-determined life, and participation, understood as the right to contribute to and benefit from various aspects of society, are fundamental rights which need to be fully recognized and implemented also for older people.

EURAG's mission is to promote social, economic and cultural development in society which raise the recognition of the value and the contributions of older persons, to improve their integration in society, to reinforce the prevention of any kind of adverse discrimination on grounds of age, to improve the living and working conditions and the quality of life of older persons through the full development of their potential by creating the necessary enabling and supportive environment offering appropriate training opportunities and self-determined retirement flexibility. EURAG also presses for effective policies and measures having the objective to enable older persons to lead as much as possible the maintenance of an independent life, to strengthen participation in decision-making pro-

cesses and care support, to offer high quality social and health services, to safeguard their financial security, not least by adequate income and protection of their savings, to provide access to life-long learning, to guarantee their easy access to culture and leisure, to promote their self-help activities, and to secure adequate representation of their interests in society. In all these areas EURAG gives particular attention to the situation of the most vulnerable and disadvantaged.

In working to achieve its mission, EURAG seeks effective cooperation with governments, international and intergovernmental organizations and agencies, the European institutions, non-governmental organizations, the scientific world and other advocates for the conception, the implementation and the monitoring of appropriate policies and programs which correspond to the needs, aspirations and capacities of older persons.

EURAG believes that a non-governmental advocacy organization should, in the first place, preserve its total independence and act with the full involvement of its network of members but also in cooperation with a wide range of other local, national and international level organizations and individuals which have compatible objectives.

See: <http://www.igm-formation.net/>

<http://www.info-alzheimer.be/newsdetail.asp?newsid=132&lg>

http://www.pflege-charta.de/nn_454/DE/Die__Charta/Pr_C3_A4ambel/pr_C3_A4ambel__node.html?__nnn=true

Gordon Lishman [ACE/UK]

It is important that articulate, informed, supported older people participate in the design, implementation and review of services for older people and in inspection, review and scrutiny of those services.

Representative older people's organisations may be more concerned with issues that affect most older people rather than the problems of the minority who receive health and care services at any one time.

Organisations which campaign with older people can have an important role in drawing attention to abuses and to systemic failings (e.g. on nutrition and help with eating). They can also contribute to identifying solutions and achieving wider political and public support for them.

Elizabeth Mestheneos [AGE/GR]

For those of us in the EU, influencing the numerous EU institutions and the Member States is a critical way in which we can change policies and actions at all levels to benefit older people living in the EU and in particular the most vulnerable. AGE –Platform, with its very large and growing membership, has become a major advocate for older people ensuring their voice is heard, including the opinions and needs of the most vulnerable.

AGE's fundamental principle is that older people should speak for themselves and ensure their voices are heard at the EU level. With its growing membership of over 150 Members including 10 European-wide organizations and 120 national or regional-level associations and 21 Observer Members (NGOs outside EU, research centres etc) AGE represents at least 25 million older people across Europe and with their active participation in AGE work, we seek to promote and defend the interests of the 150 million people aged 50+ living in the European Union.

The aims of AGE include voicing and representing the interests of older and retired people as well as promoting greater intergenerational solidarity; improving the dialogue and cooperation between its members and the European Institutions; supporting networking between older people's groups in Europe; disseminating information towards its members and influential decision makers and cooperating with other EU level NGOS e.g. Alzheimer societies, EuroCarers, who are involved with the support of the most vulnerable and their carers.

AGE-Platform and its member organizations are committed to working to promote and guard the interests and inclusion of the most vulnerable amongst the elderly and ensuring their voice is heard at national and EU levels. We try to ensure this in our working groups, covering themes such as social inclusion and the fight against poverty; social protection (pension reform, minimum income); health care and long term care of the elderly; new technologies, accessibility and transport and the active participation of older people, including the most vulnerable. We also participate in EU funded programmes which promote the interests of the most vulnerable in our societies e.g. EUSTaCEA, the Daphne programme, or Ambient Assisted Living programmes.

One of AGE objectives is to achieve European mandatory quality standards for long term care. Older people in need of long term care are very vulnerable and need protection to ensure that the services they get when they become dependent are of quality and free of elder abuse.

Vulnerability is not confined to anyone's age or period of one's life, but sickness, frailty and disability lead to dependence on others. Families, carers, service organizations and public policies all play important roles in supporting vulnerable people and AGE tries hard to ensure the needs of both care recipients and care givers (both formal and informal) are heard at EU and national policy and political levels.

NGO's PANEL REPORT

Core topics: The position and role of the senior citizen's organizations (issues concerning of the dignity and frailty) or "NGO perspectives on the human rights of older persons"

Key questions: Civic responsibility in the protection of the dignity and safety of the elderly

ARGUMENTS:

- age makes difference – the results may be double or triple jeopardy
- we have to recognize dignity as an absolute need of all people
- to ensure the dignity of elderly people we have to ensure that they will be independent (that means especially to ensure their financial independence)
- NGO should have leading role in the implementing of rights of older people
- we have to connect the work of NGOs and elected representatives

REQUIREMENTS:

- we have to recognize the unique human rights of older people
- to elaborate a multidisciplinary approach to incorporate the concept of dignity to all activities. We have to implement the concept of dignity especially to long-term care and to support the caregivers.

- we have to improve coordination of health and social services to promote dignity
- human rights are not a single concept – various groups battle for their interests. We have to balance the individual and group rights. We also have to embed the concept of human rights and dignity into particular community. We have to address the various human rights – the multiple discrimination
- we need a strong framework of human rights that would provide us a guidelines for social policy
- the human rights convey not only rights but also obligations – we have to look also at the right and obligation of cares not only elderly
- we need a good quality standards for long term care
- we need disaggregated statistics by gender, ethnicity, age

IV. CONCLUSION & RECOMMENDATIONS



Introduction

The autonomy, dignity and mistreatment of older people go to the heart of the relationship between the citizen and the state. Each has rights and responsibilities that come into sharp focus as populations age and barriers arise to personal fulfilment and social participation. Not to address them would threaten the mutual support between generations, and popular consent toward wider political and social systems. It may also ignore the abuse and neglect of some of our most vulnerable citizens. There is a need to address the adoption of preventive measures and supportive environments for both active and frail older people, who live alone, in families, in institutional care and in their communities.

The Declaration of the European Conference on Care and Protection of Senior Citizens brings together the thoughts and conclusions of policy-makers, non-governmental organisations, business and scientific interests from across the European Union. There follows a series of summary points, arising from the conference and collated by a working group, which acts as a front-piece to the Declaration itself. The front-piece suggests Areas of Special Priority and Actions that can be taken forward by the European Commission.

Areas of Special Priority

Recognising Frailty in Old Age

A focus on active ageing and strategies aimed at the 'young old' have led to an under emphasis on forms of frailty associated with old age. In deep old age, dignity becomes an increasingly important issue as the possibilities for autonomy become reduced. Responding to frailty and recognising dignity require a combination of medical, psychological and social factors to improve wellbeing and continued social integration.

WE RECOMMEND:

- Health and social services actively strengthen dignity through tailored measures that support one's meaning of life, sense of coherence and self-respect.
- A combination of medical and other interventions be used to enhance dignity via diagnostic approaches for its impairment and including interventions for its restoration.

- Dignity is to be positively constructed, supported, intensified and strengthened including comprehensive preventive measures in the frail people at risk.
- Introduce the term „dignitogenesis“, stressing the extraordinary importance of dignity and the need of active approaches that prevent forms of abuse and neglect

Recognising Diversity in later life.

As populations grow older they also become more diverse. This reflects an increasing interdependence of physical, psychological and social factors that give rise to a wide variety of coping strategies and lifestyle. It also reflects increasing diversity in the wider population occasioned by population movement, uneven economic distribution and changing attitudes to and expectations of later life.

We recommend that each of the following issues is formally recognised in future policy development:

- It is often overlooked that later life consists of different stages. These would include a third age associated with autonomy and activity, and a fourth age associated with threat on dignity due to increasing frailty. Each has different health, social needs and appropriate forms of social inclusion.
- Economic diversity and cumulative inequality across the lifecourse influence the life chances and well being of citizens in late life. These differences are influenced by gender, ethnicity, culture and locality.
- Patterns of care and support vary between member states and within different localities. The meaning attributed to old age, the role of intergenerational relationships and the balance between public and private provision, expectations state, community and family support also create variation in the experience of old age, positive and negative.

Promoting Facilitative Environments

In order to adapt to a changing balance between age-groups, it is important to create facilitative environments that promote social participation and allow intergenerational relationships to work well. Well designed environments can increase intergenerational solidarity, promote public health and increase efficient energy use. Environments that enhance the ability of older people to ambulate and exercise, for example, also create

a more active and healthy older population. Services that facilitate the negotiated shared use of public space can increase solidarity between generations.

WE RECOMMEND:

- At an infrastructural level, the promotion of age friendly urban and rural design, including housing, transport and the use of public and private space.
- Enhancing social integration through the research and dissemination of factors that facilitate intergenerational cooperation and shared problem solving in community settings.
- An examination of the role of the media in influencing attitudes toward different age groups and intergenerational interaction.
- That mistreatment be recognised as a problem of failing care and support, which can be addressed through the development of supportive systems and environments.

Promoting Family Solidarity.

Families and the balance between family care, health and welfare support are key components in the maintenance of intergenerational solidarity within families and in removing the circumstances within which mistreatment may arise. Family relations form a continuum from supportive and caring to dysfunctional and even toxic family structures and environments. In order to promote the former and remove the circumstances in which abuse and neglect occur, we would recommend:

- Generate further knowledge about the dynamics of families with older members and the identification of risk factors for mistreatment
- The development of partnerships between families, elders, the State, communities and civil society
- Facilitate families in their caregiving role by developing services, work friendly policies, and further the development of a continuum of support including Long Term Care
- Promote a comprehensive policy agenda combining family policy and aging policies

Building a continuum of Long Term Care (LTC)

We have to re-assess the concept of LTC and recognise the importance of both continuity of care and that care needs reflect a continuum that changes as adults age. This would include formulating a new culture of care through promoting an holistic model that increases quality of care and would be sensitive to aging needs and overcome forms of mistreatment. In order that LTC services should be physically and socially accessible to all, we would recommend:

- Improved coordination between health and social care services.
- Rehabilitation into community settings should be prioritized wherever possible
- Facilitating a continuum of care that addresses changing need, including palliative care
- Increased communication and coordination of inter professional interventions involving consumers, elders and families in care planning.

Health Prevention beyond a Disease Model.

We find it necessary to highlight, not only at the medical, but above all at the general and political level, specific health problems of the frail elderly people beyond the disease-model. It is very important to understand that to want a medical care of high quality for the elderly, is also to recognise that health is more than an absence of disease. Misunderstanding and under-estimation of social and psychological factors can lead to cases of systematic abuse and neglect with a substantial decay of abilities of older patients and health-related quality of life.

WE RECOMMEND:

- Greater attention to preventive measures, their dissemination and factors affecting uptake.
- A combination, rehabilitative, and integrated interventions to reduce reliance and negative impacts on hospitalisation
- Greater use of the psychological and social intervention on recovery
- More effective translation of scientific innovation into effective medical intervention.

Preventing the Misuse of Pharmacology

While advances in pharmacology can significantly improve the well being of older patients, it is liable to mis-prescription, a non consideration of alternatives and may used as a form of social control. Increased awareness of multimorbidity and the use of alternative approaches to ineffective overprescription of pharmacological drugs. Even the drugs prescribed in harmony with guidelines for treatment of particular diseases can lead, in the framework of polypragmasia to serious deterioration of frail geriatric patients.

WE RECOMMEND:

- Prevention of chemical abuse: the use of pharmacological products as a means of restrain and control.
- Prevention of misprescription, which can constitute a form of financial abuse
- Greater use of prevention, comprehensive rehabilitation, psychotherapy and other non-pharmacological interventions to improve the wellbeing of older patients.
- Holistic support for frail people beyond a disease-model, to relieve for example, from falling, muscle weakness, depression and anxiety, resignation.

Promoting Conceptual Development

The study of autonomy, dignity and mistreatment in old age is conceptually underdeveloped. This is often overlooked in the search for practical measures. However, clear theoretical understandings are necessary if responses are to be sustainable in the long term. This is particularly true of the multiple and interacting factors that influence intergenerational solidarity and well-being in later life. Understanding of the systems and dynamics influencing behaviour is much more advanced for other parts of the life course- for example childhood- and it is time for old age to catch up.

WE RECOMMEND THAT DEVELOPMENT WORK IS NEEDED INTO THE FOLLOWING:

- The complex systems of intergenerational relationships, in families, workplaces and in communities.
- The adaptation of organisational cultures, in public and business sectors, to periods of rapid demographic change.
- The relationship between human rights, social inclusion and elder mistreatment.
- The philosophical meaning of longevity and later life

Building Education, Training and Learning

If education and training remain at current European levels, an under-capacity in helping professionals is inevitable. Therefore appropriate training of professionals, para-professionals, care workers and family carers, requires special attention in order to develop knowledge, share and disseminate this knowledge. There is also a need to see education in a broader context, embracing understanding between different generations.

WE RECOMMEND:

- Mainstreaming lifecourse and aging into schools, higher education and professional curricula.
- Development of specialist programs and departments in both Gerontology and Geriatrics at Masters and doctorate levels.
- Facilitating prevention through educational programs such as health promotion and educating the young in schools, and promoting learning programs for elders in university settings such as the University for the Third Age.
- Broadening research bases and dissemination of evidence through community-university partnerships as well as partnering with the business sector.

Suggested Actions

1. THE EUROPEAN COMMISSION SHOULD INCLUDE THE ISSUE OF DIGNITY AND MISTREATMENT IN THE PRIORITIES ADDRESSED IN THE FRAMEWORK OF THE OPEN METHOD OF COORDINATION ON LONG TERM CARE:

- The EC should ask Member States what they do or plan to do to tackle the issue of dignity and mistreatment in the questionnaire that MS are asked to return once every three years to the EC with information on their LTC system and policies;
- The Social Protection Committee should organise regular Peer Reviews on the issue of mistreatment, the quality of LTC and age-friendly environments;
- The EC should support research on conceptual understanding of elder abuse and neglect and complete the collection of prevalence data across the EU-27 and policies/measures which have proved useful to fight against elder abuse.

2. THE EC SHOULD INCLUDE A WHOLE CHAPTER ON DIGNITY AND MISTREATMENT IN THE COMMUNICATION ON LTC THEY PLAN TO ISSUE IN 2010:

- This chapter should build on the EC Conference of March 08 and French Presidency Conference of October 09 on Alzheimer's Disease, CZ Presidency Conference of May 09 as well as the Swedish Presidency Conference of September 09
- It should also make concrete proposals for EU action to tackle elder abuse institutional, community and home care settings and promote environments that support autonomy and dignity.

3. THE EC AND MS SHOULD ADAPT STRUCTURAL FUNDS REGULATIONS AND PRIORITIES TO ENCOURAGE THEIR USE FOR THE IMPLEMENTATION OF QUALITY LTC AND COMMUNITY SERVICES FOR THE ELDERLY:

The Ad Hoc Expert group working on de-institutionalisation of care services will deliver a report in October and their recommendations should be used to make it more easy for local and national authorities to use Structural Funds and European Social Fund resources to tackle the issue of elder abuse, the development of preventive environments, the promotion of well being of elderly dependent people and the concept of Design-for-All.

4. THE MS AND EC SHOULD IMPROVE THE LEGAL FRAMEWORK PROTECTING VULNERABLE CITIZENS' GROUPS SUCH AS THE DEPENDENT ELDERLY INCLUDING COMBATING AGAINST ABUSE OF GUARDIANSHIP IN ELDERLY PEOPLE WITH DEMENTIA AND CONFUSION:

- MS should support the EC proposal for a directive to combat discrimination outside employment on various grounds including age;
- Since LTC services fall in the scope of the Services Directive and there is now a single market for services, free movement of care professionals and free movement of patients, the EC should take the initiative to propose mandatory quality standards for LTC services to protect this vulnerable group of consumers as exist already for the protection of consumers of goods and products in the EU.
- The EC should propose the development of EU coordination between MS justice systems to prevent staff who have been convicted of elder abuse in a country to move and seek work as carer in another MS.

Attachements

1. Declaration of the conference

2. Program of the conference

3. For further information on the conference please see video footage which is available on the website below or on an enclosed CD with power point presentations of contributors.

Link to video footage: <http://EU2009.VisualGate.cz>

“Will and support for meaning, dignity and respect”

Declaration of the

EUROPEAN CONFERENCE ON CARE AND PROTECTION OF
SENIOR CITIZENS

The Dignity and Hazards in the Elderly

Continuous increases in life expectancy over the last decades strengthen the hopes of most people for a fuller use of their potential and for increasing their contribution to close relatives, families, communities and society as a whole.

However, taking advantage of prolonging life in old age usually requires active creation of certain preconditions, active removal of various barriers and obstacles which hinder personal satisfaction and self-fulfillment, and social inclusion, as well as well-being and security.

Until now, increasing life expectancy and the rising proportion of seniors in populations has been a major source of concern rather than grounds for coordinated planning supported by strong political commitment. Although ageing has been recognized as a challenge in relation to pension and health systems, and to labor markets, which are important preconditions for competitiveness and quality of life of current and future generations, it is also necessary to pay greater attention to the aspects of ageing related to human rights, equal access to health, education, housing, social and other services and goods which should be adapted to the needs of frail, disabled or other disadvantaged seniors.

Frail older people with low levels of health potential (with low levels of intertwined hardiness, resilience and adaptability) are especially disadvantaged and at risk. Hazards for old people associated with unadjusted (maladapted) services and practices suitable for younger population are often underestimated as well as their desire to live meaningful fulfilling lives. Among the key values of meaning for frail older people are also issues of dignity, respect and self-owning – maintaining the uniqueness of each personality and real competencies in decision making.

Economical and cultural development in the European Union and in many other countries offers favorable conditions for the development

and systematic, generally accessible, implementation of “long-term care” (LTC) services as qualitatively higher degrees of support and security for frail people at risk or in situation of lost capacities for self-care.

The strength of the concept of long-term care (LTC) lies particularly in the coordinated, seamless provision of services and interventions and in breaking down the existing barriers between various sectors, institutions, competencies, professional boundaries and payment mechanisms. Furthermore it relies on an emphasis on the meaningful existence of human beings, enabling life in familiar environments while maintaining autonomy and social roles. It also relies on active prevention and on early detection of various forms of mistreatment by ‘caring’ persons (relatives, or professionals), various forms of neglect, abuse or even violence (domestic violence, misuse of restraints etc.).

Dignity, self-esteem and security must not be put at risk even for the most frail seniors and seniors at greatest risk – those who are dying, unconscious, severely disoriented (confused, or those in severe delirium) or suffering from advanced stages of dementia. Even they must not become the objects of cheap provision for basic biological human needs.

Limited public resources require that greater emphasis is placed on the expediency of long-term care (LTC), including active monitoring of care and the use of high technologies. Those, together with active counseling, supervision, and other forms of support for caring families and for professional teams, are the cornerstone to prevent excessive burden, burnout and failure.

The right concept and setting for a health service system is exceptionally important for the struggle for the quality of life in old age. The level of functional health is amongst the key factors of quality of life. At the same time, non-discriminate support for health, including availability (accessibility and affordability) of health services is a fundamental mark of the equal position of older persons in society. Furthermore, it is necessary to strive for subordination of health care provision to the essential need for meaning of life and not to allow replacement or overlaying of natural social roles in relation to decremental changes and multimorbidity with the role of „lifelong patient”, subordinated to the powers of health professionals and of regimes of health care. It is thus important to put an emphasis on the key health problems and challenges.

Following on from the French E.U. presidency, which focused on Alzheimer disease, neurodegenerative disorders and dementia and other issues related to dignity, the Czech E.U. presidency wishes to emphasize the critical importance of the phenomenon of geriatric frailty, i.e. treatable, and thus fully in the competence of health interventions and services, aspects of the decrease in health potential (mutually interrelated hardiness, resilience and adaptability) and frailty-determined multi-causal health problems beyond the limits of the so called “disease-model”.

Many health problems in old age remain out of the interest of health institutions, untreated and not confronted, despite the repeated warnings and calls from various geriatric societies (IAGG, EUGMS, SGMEUMS). The structure of health services, developed over time with an emphasis on the needs of young populations as well as the structure of education of physicians and other health workers do not correspond to and confront current health problems.

Frailty and its clinical consequences are thus becoming a source of misunderstanding, unnecessary suffering, discrimination, neglect, preventable disability, avoidable social exclusion, unnecessarily bad prognosis of various diseases and accidents and altogether represent severe health challenges for the dignity and security of old people and the touchstone of quality of health and social care.

The Prague conference builds on previous EU presidencies, conferences, recommendations and both political and expert documents of European meetings and negotiations, including

Meeting and recommendations of the conference „The fight against Alzheimer's and related diseases“ held during French presidency of the EU in October 2008 in Paris

Meeting and recommendations of the conference “Intergenerational Solidarity for Cohesive and Sustainable Societies” held during Slovenian presidency of the EU in April 2008 in Brdo, which focuses inter alia on long-term care in intergenerational perspective

“European silver paper on the future of health promotion and preventive actions, basic research, and clinical aspects of age-related disease” adopted at the conference held during French presidency in September 2008 in Wrocław, Poland, and supported by EUGMS, IAGG-ER, EAGP, ISG and ISSAM.

Discussion paper of the European Commission „What can the European Union do to protect dignity in old age and prevent elder abuse“ a following conference on elder abuse held in March 2008 in Brussels

“Healthy ageing: keystone for a sustainable Europe – EU health policy in the context of demographic change” (2007, discussion paper)

Communication of the EC „Demographic future of Europe - from challenge to opportunity” (COM(2006) 571 final)

A position paper „Ageing and Health in Europe – Challenges, opportunities and the role of Specialist Health Care for Older People“ for the UNECE Ministerial Conference on Ageing (Berlin, 2002) from the EUGMS and the SGMEUMS

Meeting and recommendations of the conference „eHealth 2009“ held during Czech presidency of the EU in February 2009 in Prague

Madrid International Plan of Action on Ageing (MIPAA) adopted by the Second World Assembly on Ageing, held in Madrid in 2002

The United nations Principles for older people adopted by the General Assembly of United nations in 1991

European charter for family carers supported by the Confederation of Family Organisations in the European Union (COFACE) in 2009

WITH RESPECT TO THE CHALLENGES AND OPPORTUNITIES AND IN ORDER TO SUPPORT DIGNIFIED, ACTIVE AND HEALTHY AGEING AMONGST EUROPEAN CITIZENS, THE PRAGUE CONFERENCE AND PARTICIPATING INTERNATIONAL SENIORS' ORGANIZATIONS LOOK TO RESPONSIBLE BODIES, INSTITUTIONS, ACADEMIA, PUBLIC AND OTHER RELEVANT STAKEHOLDERS AND CALL FOR THE ADOPTION AND THE IMPLEMENTATION OF THE FOLLOWING RECOMMENDATIONS.

We look particularly to:

A) European Commission and national governments

1) CHANGES IN APPROACH TO THE OLD AGE:

a) Try to ensure that demographic development and arrival of the longevity society are not perceived one-sidedly from the perspective of demographic alarmism or the demographic 'timebomb', which is based on the fear of lack of resources for social security and health systems, but are also seen as an opportunity and the chance to change our approach to life in old age.

b) Promote open discussions about convention on rights, responsibility, and participation of older people in society

c) Consider the effect of purposeful, single-minded (strategies for the) inclusion and integration of issues related to old age and ageing into government and parliamentary structures, and modulate any division of competencies so that they respond to demographic changes in society and the urgent need to solve them

d) Consider the establishment of an EU gerontological institution or program aimed at monitoring, education and other roles or tasks related to adjusting policies and services to the needs of ageing populations

e) Pay attention to arguments that there is continuum of “Elder Dignity, Abuse and Neglect” (EDAN) and that mistreatment of old people, including neglect, abuse or even violence, are not usually isolated phenomena, but the consequence of insufficient respect for/towards older generations, their unclear social role and lack (absence) of flexible support systems for older people with disabilities and for caring families

f) Include issues related to EDAN and adult protection services in the OMC and strengthen the cooperation and exchange of good practice and experience within the EU, including in the area of research

g) Ask the European Commission to adopt positive strategies for active, healthy and dignified ageing in the EU, which will understand ageing as an opportunity and will formulate concrete recommendations to adjust individual policies, services and goods such as housing, health, education and other services and opportunities and not only focus on the fiscal implications of demographic development, or on prolonging working life

h) Continue to remove discriminatory age barriers and to strengthen protection against (age) discrimination in various areas of life

2) RESPECT TO CULTURAL AND RELIGIOUS HETEROGENEITY

a) Acknowledge and take into account the cultural and religious diversity (heterogeneity) of today's Europe; recognize the sense of being uprooted experienced by ethnic and religious minorities; promote respect of the variety of experiences in old age and rights (rightful claims) arising

3) LONG-TERM CARE

a) Give more attention to discussion on the adoption of European-wide

principles and standards of LTC and to the European concept of geriatrics/gerontology and comprehensive rehabilitation

b) Participate in the creation of the European concept and standard nomenclature of LTC which will enable continuity of support and care as well as an exchange of intelligent and comprehensible experiences, and examples of good practice while emphasizing an enabling community model of LTC, independent living, and “ageing-in-place in the home and community.

c) Support the development and use of ICT in LTC based on the results of the conference on „E-health“, which was held during the Czech presidency of the EU

d) Minimize the impact of the global crisis on the financing of health, social and other services, which are precondition of dignified life in old age

e) Support in the maximum feasible way the de-institutionalization of social and health care services

4) COMMUNITY LIFE

a) Recognize and appreciate the meaning and dimensions of community living for older persons in home environment by a goal-seeking and permanent creation of appropriate conditions for its development

b) Appreciate the value of older persons for economic and social development including the importance of community care and support for local employment and including the importance of older people for revitalization of small rural settlements

c) Open ESF and other financial instruments in the EU to the needs of ageing populations, not only to the working population and labor markets

5) EDUCATION AND RESEARCH

a) Effective political decision making must be based on evidence. Support purposeful and efficient policy and practice-oriented research into all areas of life in old age and ageing so that the extent and quality of research projects correspond to the significance of changes in today's society

b) Recognize the importance of incorporating the needs/demands of seniors and societies marked by longevity into all levels of educational

systems and support the development of education in gerontology and geriatrics

6) PUBLIC OPINION

a) Support targeted and efficient measures, especially through the media, aimed at changing the views of society on the role of older generations within society and about life in old age

B) Local and regional authorities and their bodies:

1) CHANGES IN APPROACH TO THE OLD AGE:

a) Be sensitive to the dignity of and risks faced by frail seniors as well as to the potential of healthy and active fit seniors.

b) Do not forget that many lonely old people have no other advocate, help nor anyone to rely on other than their neighbors and their community (municipality) and that caring families need your support as well.

2) EXAMPLES OF GOOD GOVERNANCE AND PRACTICES

a) Exploit to the limit all possibilities of the information global society – opportunities to share your experiences, examples of good practice within the whole EU as well as all other developed countries

b) Appreciate the meaning of an urban environment that supports inclusion, health, security, and the adjustment of local transport, housing and other services (policies), and join the age-friendly cities movement (network), implement the principles and recommendations of the WHO Age-friendly cities project

3) RIGHT TO A LIFELONG HOME, THE SUPPORT OF LIFE IN THE COMMUNITY, AND LONG-TERM CARE

a) Respect the right for life time homes, support for ageing in the community (in place) and for adequate social services.

b) Support the inclusion of seniors into community life, in promoting their productivity and self-fulfillment.

c) Create conditions for the development of comprehensive systems of integrated community support services allowing for independent meaningful life for your frail fellow citizens – involving security of contacts, early intervention in case of emergencies and a senior-friendly provision of quality services

d) Strive to map and address gaps (“white places” and “no-man’s land”) in the services systems and negative competence conflicts on the edge (margins) of responsibilities of different government departments, ministries and other public administration bodies.

e) Accept the creation of conditions for comprehensive coordinated LTC, including screening and monitoring (dispensarization) of frail seniors at risk and for symptoms of elder abuse, as part of the responsibility of local government and administrative systems.

f) Take into account the diverse experiences of ageing in urban and rural environments and be sensitive to the problem of real or symbolic displacement of seniors trapped within modern urban processes such as suburbanization and gentrification.

C) The universities, academia:

a) Pay full and thorough attention to the development of education and research for ageing and longevity societies, aimed at understanding of life in old age, support of frail old and very old people, and understanding of life in its wholeness without scientific reductionism.

b) Help to debunk groundless and one-sided demographic alarmism, which severely strengthens prejudice and stereotypes as well as age discrimination

c) Struggle to ensure that educational curricula aim not only at scientific knowledge and professional skills in specific disciplines, but also to general awareness that dignity, autonomy, and respect are indispensable for meaningful life for all human beings, including frail older people and that even highly developed services must serve to support sensitively, not to be superior to them, or to exclude them.

d) Strive to ensure that the aim of research is foremost life in old age and factors influencing its quality, not older people as research objects.

e) Strive for lively connection between research and practice so that research and development respond to the needs of practice and their outcomes are appropriate for practice and are applicable;

f) Introduce a mainstreaming of ageing into the arena of science, research and education, especially where it hasn’t been explicitly present up until now, so that this perspective may expand knowledge and

contribute to an improvement in the quality of life of seniors and their position in society (e.g. business/ trade, law, architecture, art).

D) Health institutions and systems:

a) Be aware that the decline of health potential (hardiness, resilience, and adaptability) in old age bring with themselves specific health problems.

b) A “geriatrization” of medicine requires more than increasing capacities in reaction to the higher prevalence of age-related diseases, more than some partial modification of diagnostic and treatment procedures or their availability without any age-discrimination. What is the issue is a deep transformation and evolution of medical thinking and education as well as development of the structure of health services.

c) The association between health problems, disability and health-related quality of life and concrete diseases decreases with ageing. Mere interest in diagnosis and treatment of diseases often becomes inefficient, many times even harmful. It does not correspond to the variety of biological and also non-biological factors or to strong inter-individual variability of health and treatment priorities in frail and multi-morbid patients. It therefore needs to be complemented by the provision of qualified interest in other causal and clinical factors including functional difficulties which are multi-causally determined.

d) Clinical aspects of geriatric frailty and multicausal geriatric syndromes (the geriatric giants) become priorities of geriatric medicine superseding the disease-model.

e) It is essential to sensitively subordinate medical decision making and diagnostic, treatment, nursing and other medical stereotypes to existential aspects, including quality of life, autonomy, and improving the social roles of frail older people.

f) We urgently draw attention to the fact that the health problems of frail older people are often not rightly considered and acknowledged by doctors and other health workers and thus intervention is absent or inappropriate. Frail geriatric patients are still frequently perceived as an unpopular burden. They are marginalized, because the structure of health services and disciplines created for the needs of the younger population does not reflect their problems, demands and needs. They often find

themselves in a „no-man's land“ between the interests and competencies of traditional medical specialties.

g) Such misunderstanding is especially dangerous in the initial phases of ill-health and functional decompensation amongst frail older people, because of the risk of delay. Qualified geriatric medicine and the development of geriatrics as a discipline thus should not be identified only with long-term or post-acute care but should also be available in the acute phases of disease and during hospitalization, if acute care of other specialty is not necessary. It is an analogous requirement and necessity to the previous establishment of pediatric medicine.

h) We call attention to the persistent risk of geriatric hospitalisation (hospitalism), the iatrogenic harm to older people including derogation of their dignity, the mistreatment of delirium, the inducement of immobility or inappropriate use of restraints in hospitals and nursing homes.

i) We draw attention to hazards (risks) in diagnostic interventions, which are motivated not by the benefit of patient, but the purposeless or an alibiotic quest for hypothetical disease. We call attention to hazardous indigested polypragmasia and its role in the causation of multi-causal geriatric syndromes as well as to insufficient use of non-pharmacological interventions such as physiotherapy, ergotherapy, psychotherapy, home care and social interventions.

j) We require that clinical decision making in geriatric patients is strictly based upon individual goals and aspirations, on identification and intervention (of) all treatable biological as well as other factors, rather than on diagnosis, treatment and prevention of specific diseases.

k) We call attention to the need for sufficient capacity of qualified comprehensive mobile palliative care support to enable dignified deaths for older people in their familiar environments.

E) Seniors:

a) Cultivate and express the will to meaning and to your unique individuality, strive for personal development, productivity, self-realization, and social participation at every age and notwithstanding possible disabilities and handicaps

b) Do not give up if you suffer from a worsening of functioning and your health-related quality of life with advancing age – ask for qualified

geriatric assessment and intervention for your health difficulties and ask for qualified geriatric medicine.

c) Ask your local authorities for comprehensive services and support of long-term care in your community.

d) Do not resign (reconcile) yourself to manifestations of age discrimination, to the non respect for your dignity, and even less so to mistreatment, abuse, neglect, or even domestic or institutional violence. Participate actively in solving the phenomenon of EDAN (Elder Dignity Abuse and Neglect) - „be the change, you wish to see in your life and neighborhood.“

European Conference on Care and Protection of Senior Citizens

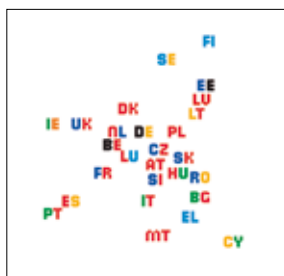
The Dignity and Hazard of Elderly

Conference in the framework of the Czech presidency financially supported by European Commission

Under the patronage of EU Commissioner VLADIMÍR ŠPIDLA and
MICHAEL KOCÁB, minister of human rights and minorities of Czech Republic



Congress Centre Prague
Prague, Czech Republic
25th -26th May 2009



Program of the conference

25th May 2009

8.00 – 9.00 Entrance 10, Registration of participants

9.00 – 10.50 South Hall, 3rd floor

Opening and introduction speeches

JAN LORMAN, Chair of conference steering committee; Chair of civic organization ZIVOT 90

MICHAEL KOCÁB, Minister of human rights and minorities of Czech Republic

VLADIMÍR ŠPIDLA, Commissioner for Employment, Social Affairs and Equal Opportunities

SERGEI ZELENIEV, United Nations, Chief of Social Integration Branch, Division for Social Policy and Development, Department of Economic and Social Affairs

IRENE HOSKINS, International Federation on Ageing, President

ROBERT BUTLER, International Longevity Centre USA, President

YANNICK VANDERBORGHT, Professeur aux Facultés universitaires Saint Louis à Bruxelles et Professeur invité à l'Université catholique de Louvain

10:50 – 11:00 Foyer South Hall Coffee break

11:00 – 12:45 Workshops I

Workshop 1.1. Council Hall III.

DECIDING ABOUT THE FORM OF CARE, RESPONSIBILITY FOR DELIVERING CARE, AND ELDER ABUSE AND NEGLECT

Key question: Frail old people in the family. Support of autonomy or permanent care?

CLEMENS TESCH-RÖMER [DE]: Frail old people in the family. Support of autonomy or permanent care?

GIOVANNI LAMURA [IT]: Burden and support needs of families caring for older people.

JILL MANTHORPE [UK]: How to identify EAN in the family, methods of monitoring

ARIELA LOWENSTEIN [IL]: Solidarity-conflict and ambivalence: testing two conceptual frameworks and their impact on quality of life for older family members

CHRISTOPHER MIKTON [CH]: Elder Abuse as a Family Violence Issue. Toxic family environment.

BRIDGET PENHALE [UK]: EAN solution methods. EAN Units practise, victims protection, the expulsion of aggressor from flats

Workshop 1.2. Council Hall IV.

IDENTIFICATION OF HEALTH DEMANDS AND CONTINUITY OF CARE.

Key question: Basic concept of Long Term Care (LTC). Hope or fiction?

ALES KENDA [SI]: Conclusion of Slovenian LTC Conference

Štefan Krajčák [SK]: Description and classification of geriatric disability (FIM, MDS, ADL, Barthel, Rankin, risk of falls)

ZDENĚK KALVACH [CZ]: Standardization of clinical characterization of frail geriatric patients – K4Care project; tbc.

SAARI TEERI [FI]: Patients integrity in LTC institutions; Network-based care - the Finnish experience

LARS ANDERSON [SE]: World without LTC institutions: challenge or fiction?

Workshop 1.3. South Hall, 3rd floor

MEDIA, PUBLIC OPINION, AND OLD AGE

Key question: Influence of the virtual second life to societal attitudes towards the elderly. How can these attitudes be changed?

RENATA SEDLÁKOVÁ [CZ]: Media generating reality; Image of old age in the Czech media

LUCIE VIDOVIČOVÁ [CZ]: Media, demographic alarmism, ageism, and lack of recognition; Sensible education for understanding old age

MARTIN DVOŘÁK [CZ] & ZUZANA JANKOVSKÁ [CZ]: Old age in the virtual second life , Image of old age in movies

SOŇA HERMACHOVÁ [CZ] Image of old age in movie'2030 - Aufstand der Alten'

Workshop 1.4. Council Hall V.

DEVELOPING AN EXPLANATIONS OF ABUSE

Key question: Current UN elder abuse typology enlarges / develops? Why – What?

SIMON BIGGS [UK]: Developing an explanation of mistreatment

ZVI EISIKOWITZ [IL] : Violence versus Abuse

GABRIELE VALENTICH [DE]: Financial abuse, practical examples: the view of a prosecutor

JUDIT KOZMA [HU]: Self neglect versus Diogenes syndrome of hoarding

THOMAS GÖRGEN [DE]: Does opportunity make the abuser? Strain and opportunity factors in elder abuse

HELENE HAMLIN [USA]: Loneliness as a form of neglect. How to identify loneliness

12:45 - 13:15

Council Hall No II

Press Conference

12:45 - 14:15

Zoom restaurant, 1st floor / Lunch

14:15 – 15:55

Workshops II

Workshop 2.1. Council Hall IV.

NATURE OF HEALTH COMPLAINTS AND DISABILITY IN THE ELDERLY

Key question: Consensus on minimum European standards in the care of geriatric patients/clients in institutional care: hope or fiction?

PAUL KNIGHT [UK]: Medicine in the end of disease era

SIMON CONROY [UK]: Defining Frailty - The Holy Grail of Geriatric Medicine. Disability in the elderly and its causations. Frailty as an age-related causation of disability.

IVA HOLMEROVÁ [CZ]: Consensus on minimum European standards of care of geriatric patients/clients in institutional care: hope or fiction?

INGRID SÖDERBACK [SE]: Process of hospital discharging frail geriatric patients.

Workshop 2.2. Council Hall III.

CORE TOPICS: DIGNITY AND ELDER ABUSE AND NEGLECT IN HOSPITAL CARE AND IN LTC FACILITIES

Key question: European Standards on restraint using in LTC

JUTTA LINDERT [GE]: Mechanical restraints outside the psychiatric departments – the threat to geriatric patients

SIRKI KIVELÄ [FI]: Chemical restraints outside the psychiatric departments – the threat to geriatric patients

LIA DAICHMAN [INPEA/ARG]: Regarding ethical issues in geriatric care

HARTMUT DOHNER [DE]: Human factor in LTC practice and the risk of caregivers' failure.

MAX RUBISCH [AT]: Quality Standards and Human Rights in Nursing Homes"

GORDON LISHMAN [UK]: Malnutrition in care settings - the UK experience with reference to the Council of Europe guidelines

Workshop 2.3. South Hall, 3rd floor

TELE-CONFERENCE PRAGUE - KIJEV

Human rights of frail older persons – Intercultural dialog

Key question: Universal concepts of human rights of older persons versus heterogeneous environment in Europe

DIRK JARRE [G]: Universal concepts of human rights of older persons versus in the religious heterogeneous environment in Europe

K. R. GANGADHARAN [IND]: Human Rights perspectives with reference to Hinduism, Buddhism, Judaism, Christianity and Islam; Book references in respect of Europe

NAINA PATEL [UK]: Minority Ethnic Elders' Issues, Rights and Actions for Decisionmakers

GALINA POLYAKOVA [UA]: Experience of Orthodox older immigrants groups

Workshop 2.4. Council Hall V.

EUROPEAN STRATEGY TO COMBAT ELDER ABUSE AGAINST OLDER WOMEN

Key question: European Strategy to combat Elder abuse against older women

ELIZABETH SCLATER [UK]: Elder abuse against older women. EA – EU scan. Prevention.

IRENE HOSKINS [USA]: Societal expectations, frailty and care needs of a growing older population. (The burden of working women who care about the ageing frail parents/relatives. Women's labour force participation rates. Risk of failure because of stress. Possible innovations.)

JIŘINA ŠIKLOVÁ [CZ]: Gender aspects of Elder Abuse

ANNE-SOPHIE PARENTS [B]: European Strategy to combat Elder Abuse against older women / project DAPHNE

15.55 – 16.10 Foyer South Hall / Coffee break

16.10 – 16.50 South Hall, 3rd floor

SUMMARY OF THE DAY

16.50 South Hall, 3rd floor

VIEWS OF THE EUROPEAN TRADE UNIONS AND THE EUROPEAN EMPLOYER ORGANIZATIONS

BRUNO COSTANTINI, General Secretary of the FERPA (the European Federation of Retired and Elderly People)

19.30 Depart in front of hotel to the place of culture evening

20.00 – 22:00 Kaiserstejnsky palace

GALA DINNER

26th May 2009

9.00 – 9.20 South Hall, 3rd floor

Opening of 2nd day

9.20 – 11.00 Workshops III

Workshop 3.1. Council Hall III.

RIGHT TO CHOOSE THE PLACE FOR LIVING – LIFELONG HOME FOR THE FRAIL ELDERLY PEOPLE WITH DISABILITIES

Key question: Good practise examples multiplication. How to do it?

AGIS D. TSOUROS [WHO/ GR]: WHO projects: Age friendly cities, Healthy ageing, and Age-friendly primary health care centre?

BARBRO WESTERHOLM [SWE]: The importance of municipalities in supporting the frail elderly – the Swedish experience (bed blocking, LTC). Tasks of governments and regional authorities in long-term care

JAN LORMAN [CZ] Community life as a basic way of social inclusion of the elderly

LADISLAV KABELKA [CZ]: Dying in place – right to choose the place for dying [palliative aspects of the long-term care]

Workshop 3.2. South Hall, 3rd floor

OLD AGE, CARE AND DIGNITY

Key question: Concept of Elderly Dignity and difficulties in its implementation

TELE-CONFERENCE PRAGUE - BERGEN

ZDENĚK KALVACH [CZ]: Dignity, elder abuse and neglect as one continuum (concept of EDAN)

WIN TADD [UK]: Dignity of the frail elderly people and the risk in health and social services

HEIKE VON LÜTZAU-HOHLBEIN [LU]: Dignity and maintenance of choices for the people suffering from dementia

VIVECO ARRHENIUS [FI]: Indicators for dignity at old age - an Finish Experience

STEIN HUSEBO [NO]: tbc.

Workshop 3.3. Council Hall IV.

ADDRESSING THE ACADEMY: COMPLEX APPROACHES IN GERIATRIC AND GERONTOLOGICAL EDUCATION TO AND SUPPORT OF FRAIL ELDERLY PEOPLE

Key question: Geriatric and gerontological education why?

DAVIS COAKLEY [IRL]: More then lectures from geriatrics: age-friendly teaching medicine in „the end of disease era“ and in the longevity society

VÁCLAV HAMPL [CZ]: Position statement of Europe Universities: Prague conference of EUA 2009

STANLEY MILLER [UK]: The Importance of Lifelong Learning for Dignity in Old Age

ARIELA LOWENSTEIN [IL]: Creating a graduate program in social gerontology

Workshop 3.4. Council Hall V.

THE GUARDIANSHIP A SERIOUS KIND OF ELDER ABUSE

Key question: Basic standards of guardianship consensus.

MAROS MATIASKO [CZ]: Analysis of the Mental Disabled Advocacy Center

SUSAN B. SOMERS [USA]: The Principles and Perils of involuntary Guardianship of Older Persons: Primary Principles of Ethical Service to Abused Older Clients

JOSEPH HOERL [AT]: Paradoxical effects of legal guardianship – the Austrian experience

BRIDGET PENHALE [UK]: The use of guardianship of older people who lack mental capacity

11.00 - 11.15 Foyer South Hall / Coffee break

11.15 - 12.15 South Hall, 3rd floor

NGOs Panel South Hall, 3rd floor

CORE TOPICS: THE POSITION AND ROLE OF THE SENIOR CITIZEN'S ORGANIZATIONS (ISSUES CONCERNING OF THE DIGNITY AND FRAILTY) OR "NGO PERSPECTIVES ON THE HUMAN RIGHTS OF OLDER PERSONS"

Key question: Civic responsibility in the protection of the dignity and safety of the elderly

ELIZABETH MESTHENEOS [AGE/GR], IRENE HOSKINS [IFA/USA], LIA DAICHMAN [INPEA/ARG], BRIDGET SLEAP [HAI/UK], GORDON LISHMAN [ACE/UK], SIBYLLE REICHERT [AEIP/B], GISLI PALL PÁLSSON [EURAG/ICL]

12.15 - 12.45 South Hall, 3rd floor / Reports from workshops

12.45 - 14.00 Zoom restaurant, 1st floor / Lunch

14.00 - 15.30 South Hall, 3rd floor

Conclusion

SIMON BIGGS & ZDENĚK KALVACH: Professional evaluation of the conference

ELISABETH MESTHENEOS: Concluding remarks NGOs

AGIS D. TSOUROS: WHO- statement to Conference

MAX RUBISCH: Concluding remark of Social Protection Committee of EC

JEROME VIGNON : Political evaluation of the conference

MARIA LARSSON: Invitation for the follow up Swedish conference on LTC

Representative of CZ government: Concluding remark

Poster Section

THERE WILL BE PRESENTED AN EXHIBITION I HAVE BEEN YET HERE BY NON-GOVERNMENTAL ORGANISATIONS DURING THE CONFERENCE.

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