Key-note speech by Dr Hon Bengt Westerberg, President of the Swedish Red Cross, former Minister of Social Affairs, in Bergen, September 5, 2010

Dignity for the frail old in a mature society

Even since I saw the first draft program for this conference, I've feared this moment. What remains to be said after almost three days of comprehensive, inspiring and engaging speeches and discussions? Very little, I feared. And I'm afraid I was right.

So I beg your pardon if my speech will mainly be reiterations of what you've already heard.

Let me start by claiming once again what we learnt alreday on Thursday: life expectancy is growing. One hundred years ago it was about 55 years for a newborn in our part of the world, now it's 80. Some people think that as much as half of the girls born to-day will reach the age of 100 years.

The main reason is not that healthy individuals live longer lives, but rather that mortality in all ages, not least for young and middle aged, has decreased. The chances to survive from serious diseases, like cancer and heart attack, have increased dramatically. Technology has not only added years to life but healthy years.

Experiences from all over the world also show that with lower mortality follows lower fertility. Both these trends contribute to aging societies.

When people lead longer lives they get more opportunities to make new exciting experiences, for example to see not only children and grandchildren, but also great grand children and sometimes even more.

Some years ago I read about Elizabeth Bolden from the USA. She had died at the age of 116. She was before she died at the time the oldest person in the world. At the last count of descendents she had two surviving children (out of seven), 40 grandchildren, 75 great-grandchildren, 150 great-great-grandchildreen, 220 great-great-great-grandchildren and 75 great-great-great-greatgrandchildren. That adds up to more than 560 descendets, and according to the article quite a number of them attended her funeral.

This case was exceptional. That's why it was reported in the media. But similar experiences will be more common in the future.

And of course longer lives mean larger chances for a lot of other kinds of adventures than more descendents.

It's important to say that not all old people are frail. I know that you know, but according to WHO, one of the prevailing global myths about elderly is that they are all frail. So it has to be

said: that is true only for a minority of them (or perhaps I should say us as I recently turned 67).

We have all heard about the concept of *the third age*. The British historian Peter Laslett, who, I think, was the one to introduce the concept, talked about the age after retirement, when you have a fundamental economic security and no real restrictions of activities due to ill-health or disability.

Other writers have set the start of the third age even earlier, at 50 or 55, when in many families the children have moved out and some people get a feeling that suddenly they have oceans of free time.

In some Norweigan surveys the respondents have been asked what they mean with elder and old, respectively, and the answers given with 24 years interval have been compared. In the middle of the 70's the respondents said that you become elder at 70 and old at 72-73. 24 years later they said that you become elder already at 64 but not old until 77. What could be regarded as the third age had extended from 2-3 years to 13 years in a quarter of a century.

Accordning to another study, carried out in Sweden, seven out of ten people said that they feel and look younger than their chronological age. More than half of the persons between 75 and 85 said that they look ten years younger than they are, that they feel 20 years younger and that they want to be 30 years younger.

That might reflect that they are still hungry for adventures, but realise that they will not have time enough to make them all come true.

Even though we lead longer lives, and objectivly during the life course have more time at our disposal, for many people in modern societies, time has become a more important restriction for consumption and adventures than money.

I've money enough to buy more books than I've time to read them. That's why I will die with a pile of unread books at my side.

The number of people in my country who experience the third age, the one starting at 65, has tripled in one hundred years. The figures are similar in other countries. I think this must be regarded one of the biggest social revolutions of the last century, and it continues.

There are different theories what our life courses will look like when we live longer.

The most optimistic theory, or concept, is what is called *compression of morbidity*. The idea is that we add more healthy years to life than years to life length. That would mean a shorter period of morbidity. More people would fall down dead on the spot, or after a short time of ill-health. Of course, this is an attractive alternative from both a social and an individual perspective, but unfortunately is gets little support from research.

Two other theories, or concepts, seem to be more realistic.

One is called *postponement of morbidity*. The idea is that for most people a fourth age will follow, when they become more dependent of external help. The theory is that this period will remain at the same length as now, but be postponed, will come after some healthy years that you have added to life.

A more pessimistic theory is called *expansion of morbidity*. It is based on the belief that health care will make it possible for more people with incurable diseases to survive, but at the same time they will become more dependent on external, and costly, services of different kinds.

I think you can find some scientific support for both those theories. It's too early to draw any final conclusions how strong each of these trends will be. But it's very probable that they will both on, a social level, contribute to the future development.

What we know for sure is that frailty increases with ages. In Sweden the number of people between 65 and 79, who receive eldercare from the municipalities is only about five per cent. The number among people above 80 amounts to 36 per cent.

Still, this means that almost two thirds of those who are 80 plus do without any help from the local authorities. But again, the number with needs grows with ages. Among those over 90 two thirds receive municipal support.

Health care is even more concentrated to the last years of life. Although those who will die in the next three years constitute only 2,5 per cent of the population, they consume 25 per cent of the resources of the hospitals.

Some years ago, a very interesting study was reported from the municipality of Larvik in Norway. All people who were 80 years old and more in 1981 were followed to their death. The last one died in 1999.

On average they got some kind of municipal support during their last 6-8 years. Perhaps that could be seen as their fourth age. A little more than half of the population had more or less full time support during their last four years. 30 per cent got only little support, at least until the last three months.

Sweden was the first country in the world to reach an above 80-population of more than five per cent of the total population. Italy, Japan and others are catching up, but I think we still keep the lead position.

This experience has stimulated an ongoing discussion on eldercare and the challenges of demographic changes, and has forced municipalities and others to prioritise and find new solutions.

One example of what has happened. In the middle of the 70's we had about 225 000 people over 80. At the same time a larger number of people, 250 000, got municipal home-help. Since then the number of people over 80 has more than doubled, while the number of

receipients of home-help services has halved. To-day less than a fourth of those over 80, and living at home, receive municipal home-help.

Of course, one reason might be that fewer people need help, and that is, in fact, part of the explanation. A 80 plus person to-day is, on average, healthier than someone of the same age yesterday. But that is not the whole truth. It has also become more difficult to get help, given the same needs. With growing numbers of elder people, and with financial restrictions, local authorities have felt forced to prioritise and, consequently, have concentrated care and services to the most needy.

This trend raises at least two questions.

What will happen in the future? Can this development continue?

And can anything be done to compensate those who will not get municipal support?

In Sweden, as in many welfare-states, eldercare is funded mainly with taxes. In recent years there has been a growing resistence to tax increases, and an increased pressure on public authorities to prioritise and become more efficient. What I just said about home-help is a reflection of that. But we can also see that there is a big difficulty to increase the productivity and efficiency in some sectors, among them eldercare.

Between now and the middle of the 2020's the number of people over 80 will grow with 50 per cent in Sweden, from just below 500 000 to about 750 000. In many other countries the development is even more dramatic.

Even if we who will be 80 in the 20's do our best to keep healthy and in good shape, the number of people in need of assistance will increase substantially. And it has become more difficult to meet their needs by prioritisation and reallocation as resources have already been concentrated.

Most forecasts forsee a growing gap between needs and available resources.

Technological development contribute to making especially health-care more efficient. Each operation is often cheaper now that 20 years ago. But technological development also opens up for new patient groups. You do coronary operations on old people today that you didn't do in the 90's, just to mention one example. The experience so far is that growing demand takes more than progress in productivity which means that cost increases.

That's one reason for the expected gap to grow. The other, as I already touched upon, is the limited possibilities to increase productivity when it comes to care. Providing conditions for dignity takes time, and time is becoming more expensive.

So what can be done to reduce the gap? One Swedish writer has called that question the climate question of welfare. And of course, there is no simple answer to it.

Recognizing the difficulties to rationalise elder care, I still think it's possible to become more efficient in some respects. For instance, many who are actively involved in the area think that multimorbidity among old people is badly and costly handled, at least in Sweden.

Many of the patients have to meet with many different physicians and others professionals, dealing with different diseases, they are ordinated many different drugs and rehabilitation programs. But there is little cooperation and coordination. Sometimes they even get drugs that counteract each other.

"Conductor missing" is the title of one of the books published on this issue in Sweden. The belief is that conductors might contribute to a more holistic view and much better efficiency. When I listen to those who propose it, I think it sounds plausible.

Another possible contribution to closing the gap might be to let the users of home-help-services and institiutions for elderly pay more out-of-pocket. Today these fees contribute to only a few percent of the costs. I'm quite certain that the fees will increase, but the potential is limited. The pockets of the frail elderly are not very thick. They can't afford to pay much more. And even if the fees are doubled they will not contribute very much to solve the problem.

Some hold that this is too pessimistic, and that the purchasing power of pensions will increase substantially in the future. However, in Sweden at least, the pensions are supposed to increase slower than the salaries of the gainfully employed and thus slower than cost increases.

Some hope that market can solve the problem. Attempts are made to encourage private demand for services, for instance by tax reductions. No doubt, this makes them cheaper for the households, but unfortunately only a limited number of elderly in their fourth age will find even these tax-subsidized services affordable.

There have also been some proposals that people, before getting old, should be forced to save money for the expeditures expecting in their fourth age. Whatever you think of the idea, it's now too late for those who will be 80 in the 20's. Most of them have already retired. And it was good to hear from Wim van den Heuvel on Thursday that we have already paid more than we will get back, so it would have been unfair to let us pay (once again) for our terminal care.

Even if some of these solutions might contribute to decrease the gap, I'm personally fully convinced that we also will have to extend the traditional way of funding elder-care, with taxes. If the necessary space will be created through raised taxes, or through a re-allocation of existing tax incomes, is, I think, the big challenge for our politicians. But they can't flee from it.

However, old people, at least people in the third age, can make a contribution themselves. Many of them will be able to work longer and I think many are also willing to do that if they get the right encouragement. With more people in the labour force, tax incomes will increase without raised tax rates.

Regardless if that will happen or not, we expect our economies to grow even in the future. Economic growth is mainly a result of productivity growth, and productivity in the economy as a whole will continue to increase. We will not be shorter of economic resources, but even richer.

The challenge is of a distributional one. Those in need of eldercare will not be the same ones as those with rising incomes, so we must find ways to reallocate the purchasing power, from those living in growing affluence to those living in scarcity, among them not least the frail elderly.

The second question is if anything can be done to compensate those who have needs, which will under no circumstances be met by the municipalities. Of, course, these needs are of different kinds.

Some years ago, the Swedish Red Cross initiated a survey where old people were asked about their needs and wants. We could identify two categories.

One was the kind of needs that is met for a small number of people by the municipalities, that is traditional home-help, to clean the home and the windows, to do some other practical things in the home, to cook, to cut the grass in the garden, to clear the snow in winter etc.

The other was social contacts. Many old people become less movable, have lost their friends or have difficultues seeing them for the same reason, have children who live far away or are busy with their own lives etc. They feel isolated and lonely, and ask for social contact.

That is the case even for many of those who receive municipal help. The staff providing that has less time than before. They are forced to be more efficient. They rush into and out of the homes, they have no time to sit down for a coffee and small talk.

When it comes to social contacts the Red Cross and our volunteers can play, and already plays, an important role. We visit people in their homes, we take them on walks, help them to visit the doctor or the bank, sometimes even take them to cultural events or meetings arranged by our local branches. With growing needs there is also a need for expansion.

As the volunteers in this area are often younger old people, those of the third age, the base for recruitement is presently increasing. Obviously our big challenge is that time is perceived as a scarce resource even by retired people. But I dare to be an optimist. I think many people find that social voluntary work can make an important contribution to a more meaningful life.

An even more challenging question is if it would be possible for us to provide more service in order to help people with more practical things, like cleaning. When I’ve ventilated this possibility with my Red Cross friends in Sweden, I mostly hear objections of two kinds.

They say: It's true that this kind of services is presently not provided by the municipalities, but they should be. If we take over they will never learn.

Or they say: I'm willing to visit an old person and talk with her, but I will not use my leasure time to clean up in her home.

The first objection can easily be rejected. The municipalities will not expand their home-help-programs, they will rather become more restrictive in the future. They will continue to concentrate on the most heavy requirements that need professionals to be met.

However, the other objection can't be dismissed that easy. If we shall do anything in the area, we need volunteers, and probably volunteers of a different kind than those who serve as visitors, perhaps younger people. But are they willing to contribute? You could have your doubts.

Could there be a third way, perhaps with volunteers who get some payment but not a market salary?

I don't have the answers, but I think we should discuss the issue within our movement. No doubt, we can see a need here. Perhaps it's not about the most frail elederly, but about elederly frail enough to need more support than municipalities will provide.

In the meantime, some Red Cross branches in Sweden actually have taken a small step in that direction. They have engaged volunteers who help old people with some practical things, like moving furnitures, changing lamps, hanging curtains etc. Most of those volunteers are men in the third age.

The wishes of most old people is very well caught by the headlines in a UN resolution from 1991: independence, participation, care, selffulfilment and dignity.

During this conference we have got many good examples how dignity can be perserved among the elderly. I feel more optimistic now than when I came here that there is a chance to die happy, to die with a smile.

Perhaps the biggest threat to dignity is, after not the short-comings of health or eldercare, but of life itself.

In one of our solution groups I told my friends about my mother, who died a couple of years ago, just before her 90th birthday. Her dementia increased during the last year. She also had heartproblems and went in and out to the local hospital for treatment. Finally she couldn't stay home. She hade to move to a nursing home. It was a wonderful place in many respects, but my mother didn't like to be there. She wanted to go home. When she realised that that wouldn't happen, she decided to die. At least, that is how I perceived it.

I think she felt a loss of dignity in her last months. I don't know, even after having spent four days here, what we could have done to prevent that. Life is not always dignified. My comfort

is that my mother had almost 89 good years before the last year. And I know that she was grateful for that.

We must always do our best to preserve dignity for the frail old. But transition from life to death is so complex that I wonder whether we will ever fully understand what we should do. I think there will be conferences like this one again and again, for many decades to come. Every meeting hopefully adds to our knowledge, but as we are far from full understanding of this transitional process there is space for more meetings.