Dignity first – Priorities in reform of care services
(Stockholm, 26-27 September 2013)

Ministry of Health and Social Affairs

Part 1 Introduction

Working life and Welfare

Sweden has a high employment rate\(^1\). Especially the employment rate in the age groups 55-59 years and 60-64 years has an important impact on the overall employment rate. This is and will be a major prerequisite for our common welfare. The common welfare is mainly financed by taxes and social security contributions. The individual is well covered in many aspects of the life span. In general your life income is redistributed via taxes to cover for both your childhood and your ageing.

This generational contract functions as long as the burden on the population in the working ages is not overloaded. In our ageing society this has to be dealt with seriously and in good time to protect the system from exhaustion. The main focus at the present is to facilitate a further increase of the overall participation in and longevity of the working life.

The Swedish birth rate is not high enough to ensure a sustainable development of the population and the financing of the welfare systems. From a dependency ratio perspective immigration is necessary to us.

Sweden’s national reform programme 2013

Unemployment among young people aged between 15 and 24 was slightly above 22\% in December 2012 – see Diagram 1. Slightly less than half of unemployed young people are full-time students who have sought employment. The fact that young people become unemployed is often associated with their transition between school and working life. However, compared with other age groups, unemployed young people generally have good opportunities to find employment, which means that most young people experience relatively short periods of unemployment. For certain groups of young people, it often takes considerably longer to gain a firm foothold in the labour market than for young people on average. This is particularly true of young people with incomplete grades from primary or secondary education and for young people born outside Europe. In the 2013 Budget Bill, the Government proposed a number of temporary and permanent measures to improve the function of the labour market and to counter the weakening economy. Therefore, temporary increases were made in places in adult vocational training, apprentice training, higher vocational training, folk high schools and certain tertiary programmes. The 2013 Spring Fiscal Policy Bill proposes measures providing a further total of 14,000 places in adult vocational training, a further total of 8,000 places in practical work experience and labour market training, and an additional 2,800 tertiary education places on master and graduate engineer programmes and nursing programmes during 2013 and 2014. Vocational training was also allocated increased funds with the purpose of enhancing quality. In 2013, the level of

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\(^1\) Prepared for the Peer Review in Social Protection and Social Inclusion programme coordinated by OSB Consulting, the Institute for Employment Studies (IES) and Applica, and funded by the European Commission.

\(^2\) Active Ageing Index 2012, European Centre for Social Welfare Policy and Research, Vienna.
financial support for studies will be raised for those not registered with the job guarantee for young people.3

Diagram 1 Unemployment among young people and full-time students seeking work

The Youth Guarantee

The European Commission have launched the Youth Guarantee initiative. Under the Youth Guarantee Member States should put in place measures to ensure that young people up to age 25 receive a good quality offer of employment, continued education, an apprenticeship or a traineeship within four months of leaving school or becoming unemployed.

The Recommendation, proposed by the Commission in December 2012 as part of the Youth Employment Package, gives Member States a clear benchmark and precise guidelines for establishing their own Youth Guarantee scheme on the basis of six axes:

- establishing strong partnerships with all stakeholders
- ensuring early intervention and activation to avoid young people becoming or remaining NEETs (not in employment, education or training)
- taking supportive measures that will enable labour market integration
- making full use of EU funding to that end
- assessing and continuously improving the Youth Guarantee and
- implementing the scheme rapidly.

The European Commission is ready and willing to make available substantial financial contributions from the European Social Fund and other EU structural funds. At the same time, the Commission confirmed in the 2013 Annual Growth Survey adopted in late 2012 that Youth Guarantee schemes are key measures that should be prioritised within growth-friendly fiscal consolidation. For the Commission, investment in Youth Guarantee schemes is crucial expenditure if the EU wants to preserve its future growth potential.

3 Sweden’s national reform programme 2013.
Pension age

Sweden still has a de facto normal retirement age of 65 years. The number of hours worked is increasing among older people, but far too slowly. Since 1994 the actual pension age has increased with 1.3 years. This is not sustainable. When we live longer, we must work for a longer period, otherwise pension levels will be too low, and the dependency burden untenable and welfare funding threatened. More and more older people are in a good position to have a longer working life. An increasing number also want to work for longer, but are confronted by various obstacles in regulatory systems, agreements and working life. The Commission of Inquiry on pension age proposes a package of measures. In the report the commission proposes the introduction of a recommended retirement age, which follows the development of average life expectancy. This recommended retirement age is a clear, non-choice alternative for the retirement of older people who wish to achieve an acceptable pension level. The age limits of the public pension system and related systems will be linked to the recommended retirement age. The proposals mean, inter alia, the following:

- The 61-year age limit for the earliest age at which people are entitled to draw their old-age pension will be raised to 62 years in 2015, and according to current forecasts, to 63 years in 2019.
- The 65-year age limit for the guarantee pension, sickness compensation and other benefits will be raised to 66 years in 2019, according to current forecasts.
- The age limit referred to in the Employment Protection Act will be raised from 67 to 69 in 2016.
- The 55-year age limit for occupational and private pensions will be raised in 2017 to 62 years.

Employment rate and longevity of the working life is of essential importance to the society as a whole as well as for individuals of all ages.

Changes in morbidity and mortality

Differences in health due to socio economic factors are larger than differences between men and women. Since the mid-1990s the onset of acute myocardial infarction AMI has declined except for women in the age 35-44 years. The most positive trend is found among people beyond retirement age, especially among men.

Since 1995 the onset of stroke has diminished from 550 to 400 per 100,000 for men and from 400 to 300 per 100,000 for women.

The most common cause of death for both women and men is diseases of the circulatory system, which in 2011 was the underlying cause of death in 39 % of women and in 38% of men. However, the death rates for circulatory diseases are decreasing. In 1987, the death rate per 100,000 women aged 15–74 years was 128 and was 48 in 2011, a decrease by a little more than 60%. For men, the death rate decreased from 352 in 1987 to 114 per 100,000 in 2011.

In the municipality of Sollentuna researchers from the Karolinska Institute have evaluated a project during 1988 to 1998 where the primary care centres offered everyone a free health survey and advice on life style related topics. Since 1988 mortality due to AMI diminished in Sollentuna with 75% for men (compared to 58%
in Stockholm county) and 74% for women (47%) and onset of AMI diminished with 33% for men (27%) and 20% for women (12%).

The second most common cause of death is neoplasm (23% for women and 27% for men). Among neoplasms, lung cancer is now the most common cause of death among women, and has increased considerably since the late eighties. Prostate cancer is the most common malignant neoplasm among men. The total mortality in prostate cancer has decreased somewhat since the beginning of 2000 and there is also a small decrease in men aged 15–74 years.

For both women and men dementia has increased considerably and the mortality rate was four times as high in 2011 as in the late eighties.

**Continuance of everyday life**

The 290 municipalities are responsible for financing and providing elderly care including nursing care in most parts of Sweden. Health care at primary care centres and hospital care is a responsibility for the 21 County Councils. For many older persons the place where they already live will be the place where they receive more intense social and medical care. Between 2001 and 2011 the number of beds in geriatric clinics has been reduced from 2,766 to 1,539 beds⁶. Among the oldest, persons aged 80 or older, the average stay in a geriatric clinic has been reduced from 19 days in 1993 to 12 days in 2006. The number of persons living in special housing (or long-term care facilities) was decreased from 118,600 persons in 2001 to 90,900 in 2011. Help at home has been made possible for persons with more and more extensive needs. In 2001 help at home and special housing was nearly equally large. In 2011 the proportions have changed. Those who receive elderly care as help at home are now 70% and those who live in special housing are 30%. At the present 17.1% of the population aged 65 years receive municipal elderly care.

For those with an income corresponding to the guarantee pension level a state housing supplement can be granted. This makes it possible for the individual to obtain a home better suited to the individual’s needs. For those who need any kind of adaptation of their home the municipalities are obliged to provide for adaptation of the home. In 2011 around 76,000 cases were granted to a total cost of more than one billion SEK.

A new-built or refurbished house has to meet demands for modern standard in various aspects such as accessibility for persons with disabilities. It is nowadays much more easy to take care of the laundry when there is a washing machine in the bath room instead of in the basement of the house. The microwave oven has made it easier to prepare meals.

**Increase of family care**

When older persons continue to live on their own it also involves care from family members, other relatives or friends. Partly this is an effect of the increasing life length among men since spouses often take care of each other. In a survey performed by the National Board of Health and Welfare it is reported that more than 1.3 million people, nearly one in five people in adulthood is taking care of, helping or supporting a loved one. At least 900,000 of these are of working age. The National Board of Health and Welfare reports that family care is very common and provided by families and by friends of all ages. Care provided between people has a socio-bearing function. Attitudes to providing care are positive, but most

carers believe that the public sector should take the main responsibility. In general care giving have no major effects on quality of life, but the study shows that those who provide extensive care are at risk to have a poorer quality of life. The public health care and social care must therefore pay attention to the carers’ situation in an early stage and actively offer support and help.\(^7\)

One effect of Sweden’s high employment rate also among women is that it can’t be considered realistic to expect a further rise in family care without negative effects on the employment rate and in the longer perspective also on the national finances.

In another survey performed by the National Board of Health and Welfare persons aged 80 or more and not using elderly care have been interviewed. The results showed that 65% needed help with at least one activity. Usually they receive help from family members. Domestic cleaning is an activity where it as common to buy private help as to receive help from the family. Very few, less than 3\%, had applied for home help. Some answered they hadn’t thought of applying for home help yet, others that they were considering doing it or that their needs had recently arised\(^8\).

### Part 2 Support for the elderly

#### Elderly care scope

**Dignity first**

An amendment to the Social Services Act states that elderly care personnel must help you live a dignified and comfortable life. You decide what such a life looks like to you. It is therefore important that the elderly care personnel you meet ask your opinion and discuss your wishes. Your unique personal needs should determine the type of care you receive and thereby allow you to live life according to your wishes and situation.\(^9\)

Elderly care is nowadays not an issue related to poverty or housing needs. The main reasons for someone to become in need of elderly care is related to health and physical limitations in combination with an inaccessible environment and insufficient accessibility to services. In 2011 312,800 persons (17.5\%) aged 65 years received municipal elderly care. 220,600 persons received home help, meals on wheels or safety alarms while 92,200 persons were receiving their help in a special housing facility.

To improve efficiency, there is a need to create a better basis for comparing and following up outcomes. The Swedish Government has taken several initiatives to improve transparency in the health care and elderly care. In 2012 the fourth National Inquiry of elderly persons about their elderly care has been carried out by The National Board of Health and Welfare. The inquiry covers persons who are entitled to home services or is living in special housing. Generally, elderly persons are well satisfied with their help and their confidence in the staff is very high. Although, there are challenges left in areas such as social activities, opportunities to go outside and possibilities to have influence on when to get help.

**A person centered approach**

With increasing access to modern health care including rehabilitation programmes and assistive technology older persons can continue living in their own homes. Care

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\(^7\) Anhöriga som ger omsorg till närstående, Socialstyrelsen 2012.

\(^8\) Behovsbarometern – äldre, Socialstyrelsen 2011.

\(^9\) [http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/18739/2012-6-19.pdf](http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/18739/2012-6-19.pdf)
at home is developing into home based care. In this perspective support for family carers is increasingly important.

A person centered approach in dementia care is recommended in the Swedish Board of Health and Welfare National guidelines for care of persons with dementia diseases 2010. Recommendations in national Guidelines focus on good quality and cost effectiveness and are based on good scientific evidence.

Social innovations are needed for provision of home-help that support the older persons wish to be included and stay connected by being able to do activities at home and in the larger community. For this purpose teams of home helpers will be educated in how to enable older people to regain connections to the larger society.

Previous research from Denmark and Norway (Kjellberg 2009) has shown that special emphasis on self-care, and independence of help have not only proved to be beneficial for the person and the significant others but also cut costs for home-help and hospital care.

**Patient involvement leads to better research**

Patients with chronic inflammatory diseases have experience and knowledge that could help to improve research and care. Patient involvement is a resource that is now being used in several projects at Karolinska Institutet. Combine - an ongoing nationwide project that covers all the medical universities in Sweden but is coordinated from Karolinska Institutet - is an example of patient involvement, and aims to encourage cooperation between patients, care providers, researchers and the pharmaceuticals industry in the field of inflammatory diseases. Patient involvement is key to Combine, but here the patients are trained specifically for their role of "research partners" who provide the patient perspective.

According to a report from the Swedish Association of Local Authorities and Regions (SALAR) secondary prevention methods has proved to be successful when it comes to prevention of injuries among older persons. Those who have experienced a fall injury are highly adoptive to life style changes. It is also proved that risks can be reduced by improved management of medications.

**Recruiting and training of staff**

Besides the development of the public finances the delivery of elderly care of good quality in the near future is depending on key issues like staff, knowledge and technology. One aspect of the ageing population is that we can see risk of increasing difficulties to recruit and keep staff, both in numbers and with competence needed. The share of the staff with adequate training improves with around two per cent each year. Today around 77% of assistant nurses have secondary school training for their work. The training of staff is supported by government programmes. Also staff with special skills is needed, for example palliative care or dementia care. A recent review on the scientific Evidence on elderly care showed that there are few Swedish studies that are large enough to contribute to the development of evidence based care. The government have in budget 2013 allocated more financial resources into research on care. Training for care staff is also possible on university level.

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10 National guidelines for Care in Cases of Dementia – summary [http://www.socialstyrelsen.se/nationalguidelines/nationalguidelinesforcareincasesofdementia](http://www.socialstyrelsen.se/nationalguidelines/nationalguidelinesforcareincasesofdementia)

**The sickest elderly persons**

The Government and The Association of Local Authorities and Regions (SALAR) have agreed on a number of initiatives on developing the care of the sickest elderly. Improvements in the care of the sickest elderly are about methods, procedures and organisation. The processes concerns a total of approximately 500,000 employees in municipalities, counties and private organisations. Therefore the agreement reward the organisations facing a systematic approach supported by quality registers as Senior Alert, Swedish palliative registry, Swedish dementia register and the Swedish registry for behavioural and psychological symptoms of dementia (BPSD register). Today 17,000 assessments per month are registered in Senior Alert, and 53% of all deaths are included in the Swedish palliative registry.

**Immigrants**

In the municipality of Malmö the Migrationsskolan (Migration School) is a transnational cooperation project between Nationalt Videnscenter for Dementia at Rigshospitalet in Copenhagen Denmark and the Minneskliniken (Memory Clinic) at Skåne University Hospital. The project’s aim is to strengthen cooperation on ethnic minorities and dementia in the Öresund region. The project is co-funded by the EU Interreg IV A programme.

**Implementing new knowledge**

How to implement best practise and new knowledge to widely spread groups of recipients is another key issue. Those who work directly with persons with dementia diseases have access to an interactive internet based training programme Demens ABC (Dementia ABC). The training programme is free of charge and is based on the National guidelines for care of persons with dementia diseases 2010. So far, until spring 2013, more than 50,000 persons have completed the programme. Six similar programmes, Demens ABC Plus, targeted for other groups of personnel are under way. In September a university programme for managers in elderly care will start. More than 900 persons have applied for this programme.

Dare to ask - dare to look is another Internet based training programme with focus on mental health of older persons. The need for teamwork in care of the elderly also assumes that there is a common basis for developing health and social care as well as to provide the elderly person with the right support at the right moment. There is a great need for a common strengthening of expertise in the field of mental health in the elderly in the various professions.

**Free choice system**

The Government launched a new law in 2009, The Act of system of Choice in the Public Sector. The overall purpose with the legislation is to promote freedom of choice for the users and to strengthen individual’s possibilities to make their own choices. The reform is based on a clear ideological view that elderly persons, as well as other groups in need of social services, shall be able to remain in charge of their own life. Another goal is to promote a greater diversity of providers since that

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13 Link to The Swedish Dementia Centre [http://www.demenscentrum.se/English1/About-us/](http://www.demenscentrum.se/English1/About-us/)

14 National guidelines for Care in Cases of Dementia – summary [http://www.socialstyrelsen.se/nationalguidelines/nationalguidelinesforcareincasesofdementia](http://www.socialstyrelsen.se/nationalguidelines/nationalguidelinesforcareincasesofdementia)

increases the possibility to find something that suits the user's own personal needs and interests – which also have a positive effect on quality aspects. So far evaluations have shown that this is appreciated by the users. The legislation makes it easier for different actors to enter the commercial market of providing service and care for the elderly. The Law is a volunteer tool for those municipalities who want to expose the service and care actors in the public sector to competition and thereby let the elderly choose the supplier. Today 179 of our 290 local municipalities have applied to the free choice system. Around 900 providers are active within this system. Some of them offer services in different languages; other has special knowledge of specific treatments or diets and some providers offer cultural or religious competence. One effect of the free choice initiatives is a growing demand for staff with other cultural background than Swedish. In 2012 23% of the home help were delivered by private companies and 21% of the users in special housing were living in a private company operated facility. Free choice systems for public financed assistive devices are in development.

**A society for all**

An age friendly society is directly linked to the need for practical help, social and medical care. It is also a question of dignity to adapt society to an ageing population. Design for all in buildings and the surrounding environment, accessibility to services and useful technology can altogether contribute to make it easier to cope on your own and delay needs for more extensive care.

Each year around 1,500 persons aged 65 or older in Sweden die from fall injuries compared to 293 persons of all ages killed in traffic in 2012. Hip fractures represent the third largest reason for days spent in hospital. Only schizophrenia and stroke result in more days spent in hospital. Around 75% of the outdoor fall injuries are related to the surface of the pavements. The Swedish Civil Contingencies Agency report that the risk for fall injuries is connected to impaired balance, impaired muscle strength, medication, impaired sight and hearing, malnutrition and the surrounding environment.

The Swedish national Institute of Public Health report that fall injuries among the elderly population in 2011 resulted in 70,000 persons admitted to hospital followed by rehabilitation and care at home at a direct cost of 5 billion SEK16.

Doing things in a different and better way can reduce care costs without adding extra money. The organisation of snow removal can reduce accidents. When it is snowing 10 cm it is obviously easier to drive a car than it is to walk. The municipality of Karlskoga found that if they begin snow removal on the pavements instead of on the roads this will have a direct impact on the number of incidents where pedestrians are injured.

**Elderly persons as consumers**

**Tax reduction for Household Services**

In 2007 the Government introduced tax reduction for household services (RUT). The market for household services is growing and it is estimated that until 2011 around 12,000 new jobs has been created. With the tax reduction the customer will pay 50% of the price and the maximum reduction is 50,000 SEK per year. In 2011 148,000 persons 65 years or older used the tax reduction for household services. Around 89,000 persons (60%) of those had the lowest income (in level with guarantee pension and household supplement). For older persons it is as common

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to hire help for domestic cleaning as it is to receive that help from the family. Since 2007 the number of persons with few hours of home help within municipal elderly care has diminished with 2,100 persons. It seems that the tax reduction for household services so far only have, if at all, a minor effect on the demand for home help. It seems that the needs assessed services the municipalities are responsible for and the tax reduced household services together now cover a larger share of the older population.

**Assistive consumer products**

Despite a growing interest among users for buying assistive devices the market for private owned assistive devices is still quite small. The possibilities to buy assistive devices have by tradition been very limited since provision of assistive devices is a responsibility for county councils and municipalities at a low or no cost at all. The assortment used to be quite limited and only in specialised shops. The turnover for the four largest retail chains amounted to 73 billion SEK in 2011. In the recent years assistive devices have become more exposed as consumer products and also more available for many older persons. In most counties there are shops where customers can see, test and buy assistive devices. Buying assistive devices via mail-order is frequent but Internet shopping is rapidly increasing. Since the statistics is mainly based on the public obligation to provide for the individuals need of assistive devices the statistics for private acquired assistive devices are incomplete. Partly this is an effect of the technological development. Many assistive devices are now available as consumer products. Specialised equipment can now be replaced by regular consumer products. It is no longer obvious how to define assistive devices. We can also observe discussions on whether the cost for certain services can be accepted as assistive devices and thereby entitled to subsidies.

**Technology for the elderly**

The Government has during 2007-2012 financed the national project Technology for the elderly. The overall aim was to support development of products and services that can assist elderly people and their relatives in everyday life. The Technology for Elderly programme was coordinated by the Swedish Institute of Assistive Technology. During the first years 100 projects received support from Technology for Elderly 2007–2010. For the later period the objective was to test and develop new technology for elderly in their homes.17

**Ageing with IT**

The use of Internet has increased from 2% of the population in 1995 to 89% in 2012. The use of Internet is continuing to increase. The use of lap-top is increasing fast and so is the use of mobile equipment for Internet. Shopping via Internet is used by 72% of all users and by 65% of users aged 66-75 years and by 53% of the users aged over 76 years. 72% of all users pay their monthly bills etc. via Internet compared to 52% of the persons aged 66-75 years and 15% of the persons aged 76 years.

**Learning together**

During the Swedish Presidency of the EU in 2009 the need for sharing of experiences and knowledge was identified and addressed in the Conference on Healthy and Dignified Ageing and the following Council Conclusions. Learning together is of essential value in our efforts to take on the challenges of tomorrow. If we in a successful way can integrate and make use of new experiences we will hopefully have increased our possibilities to take on the challenges of tomorrow.

17 http://teknikforaldre.se/english
Both this Peer Review and the SPC-WG-AGE goal, namely to identify the most effective ways of ensuring that we will be able to provide adequate long-term care on a sustainable basis in our ageing societies, express this aspiration.