REGERINGSKANSLIET

Promemoria

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Socialdepartementet

Answer to Questionnaire on Health and Long-Term Care of the Elderly: Sweden

1. ACCESS

1.1 Health care

1.1.1 Mechanisms for guaranteeing access

Health care is regarded as an important part of the Swedish welfare system. A fundamental principle being that all citizens have the right to good health and care on equal terms, regardless of where they live and their economic circumstances. The following conditions are especially characteristic for the Swedish health care system:

- It is mainly a public responsibility.
- This public responsibility belongs to regional political authorities - the county councils - whose members are elected every fourth year.
- The health care is mainly financed by county council taxes, other sources of income are national government grants and dues charged by the county councils for certain services.
- The health care system is supported by a national insurance system and other social welfare services.

Since 1992 municipalities have had the main responsibility for social services and health care of elderly and disabled people. Earlier the responsibility was to some extent shared between the municipality and the county council. The government and Parliament have the responsibility of legislation and formulating guidelines for how the elderly shall be cared for and who shall provide the various services.

Every county council shall offer good health and medical services to persons living or residing permanently within the county council area. In the Health and Medical Services act (HSL), it is regulated how patients should be prioritised depending on type of medical problem. Those patients who have the greatest need of care should have priority over other patients. The ethical base consists of three principles: human value; need and solidarity; cost-effectiveness, in order of priority.

It is up to each county council to decide how to serve the population with care. The primary care sector has the aim of improving the general health of the people and treats diseases and injuries that do not require hospitalisation. This sector employs many different professional categories – physicians, nurses auxiliary nurses, midwives, physiotherapists, psychologists and, sometimes, chiropractors etc. For conditions that require hospital treatment, medical services are provided in a number of specialist's fields, partly as inpatient care at hospitals and partly at clinics. Medical competence and equipment enables treatment of patients suffering from almost all diseases, including psychiatric problems.

The total health care cost in 2000 was SEK 163 billion. This figure includes costs for pharmaceutical preparations and dental care. 16 per cent of the health care costs were paid by the households (patient fees, co payments of pharmaceuticals, glasses etc). The total health care cost amount to 7,8 per cent of GDP. If the health care cost of the municipalities is included (which is about 0,7 per cent of GDP), the total proportion will be 8,5 per cent. The costs have increased the last years.

On average, a citizen in Sweden paid SEK 2 100 in 1999 for healthcare, including drugs and dental care.

The number of visits to a doctor in Sweden is low in an international perspective, app. 2,8 visit/year. The cost per patient and visit varies between SEK 100-150 for primary care. For specialist care, most of the counties charge SEK 200 (range: SEK 150-250). The patient does not have to pay more than SEK 900 during a twelve-month period regardless of the number of visits. Most of the counties do not charge for children under the age of 20. In 17 out of 20 counties, the fee for a visit to a district nurse is free of charge. Otherwise, the fee is about SEK 40. At the maternity primary care clinics, regular check-ups are given free during the entire pregnancy.

For inpatient care there is a nationally agreed ceiling of SEK 80 per day. For patients under the age of 20 (18 in Stockholm) inpatient care is free of charge.

Regarding dental care the proportion of the cost paid by the patient has increased from less than 40 per cent in 1993 to just over 60 per cent in year 2000. Of the total dental care costs in 1999 patients paid 59,4 per cent, county councils paid 25,8 per cent and the national government 14,8 per cent. Dental care is provided free-of-charge to all children and adolescents up to the age of 19 years.

The percentage of the total health care cost that goes to pharmaceuticals has increased from 8,4 per cent in 1990 to 15,4 per cent in 2000. The patient's fee for pharmaceuticals (prescribed drugs or not) was about 26-27 per cent during 1998-2000. There is a ceiling for prescribed drugs at SEK 1 800 during a twelve-month period.

Patient fees have not been regarded as a source of income in the Swedish health care system. Patients' fees only amount to 2 - 3 per cent of county council revenues.

1.1.2 Assessment

The Health and Medical Services Act (HSL) regulates the obligation of health services (authorities) to offer care. The definition of good care given in section 2a of HSL mentions, among characteristic features, that care must be easily available. On the other hand, nothing is mentioned about what waiting time may be considered compatible with requirements for good care. According to the preparatory work to the Act, patients must be given access to good care within a *reasonable* time.

The Parliamentary decision concerning government bill 1996/97:60 "Priorities in the health services" means that since 1 July 1997 a general rule of priorities in section 2, HSL lays down that the person with the greatest need for health care shall have precedence. The bill describes certain nationally established, general guidelines for these priorities.

In addition, Parliament introduced an amendment to section 2a, HSL to the effect that any patient applying to the health services must be given a medical opinion regarding his or her health state *as soon as possible* unless this is *evidently unnecessary*. One reason given by the Government for this change in the law was that a precondition for helping a patient correctly is rapid and qualified judgment regarding the need for care and the care measures required. Further, the Government maintains that it may be difficult to apply the ethical principles of setting priorities without a good previous appraisal. This amendment involves certain clarification of the legislation regarding accessibility to care.

The Ministry of Health and Social Affairs and the Federation of County Councils have since 1992 reached annual agreements to improve patients' access to care. The agreements initially included time limits for treatment of 12 defined procedures (on certain indications). In the "care guarantee", which has applied since 1997, limits for waiting times for primary care and specialist care are specified.

The contents of the agreement currently in force are as follows. Primary care is responsible for the first contacts with the patient and must offer help the same day, either by telephone or through a visit. If the patient cannot be seen by a doctor at the first contact with the care services, it must be possible to offer an appointment with a doctor within eight days at the latest. If the care service judges that the patient needs specialist care, an appointment must be offered without delay according to guiding principles for selection of priorities; but at the latest within three months. When patients are very worried or when the doctor fears that the patient has a serious disease that will get a worse prognosis after a longer waiting time, and judges that a visit to a specialist cannot wait, the patient must be given an appointment within a month at the latest. When the doctor judges that the patient needs treatment, the treatment must be started immediately, in consultation with the patient and according to guiding principles of selection and priority setting. However, it is not stated how long a patient must wait for the treatment the doctor has judged necessary; nor do the agreements involve any legally binding guarantee for patients.

Since 2000 waiting times to certain clinics and procedures in specialist care have been reported in a national Waiting Time database on the Internet.

The particulars included in this database are:

A. New patients

- Longest expected waiting time for patients without priority.

B. Patients waiting for care

- Number of patients on waiting list.
- Number of patients that have waited more than 12 months.

C. Patients who have received care during the past four months

- Proportion that received care within three months.
- Median waiting time.
- Waiting time for 90th percentile.

- Number of planned visits to doctor (new visits).
- Number of planned treatments.
- Number of unplanned treatments.

All Swedish county councils and regions are collaborating on this database and the reporting, which is also web-based, is done three times a year. However, this does not apply to the prospective waiting time for new patients. Such information must be continually updated when waiting times change or at least once a month.

Sweden's Public Health Report 2001 notes that poorly-educated people have poorer health and higher use of care than highly-educated people. Studies of the consumption of out-patient care show that social and geographical differences are small when account is taken of indicators of care needs. This part of care, therefore appears to be given on relatively equal terms.

In some years, one question in the Survey of Living Conditions (ULF) is whether one had the need to visit a doctor but not done so. In 1988-89, the proportion of those who considered that they had a need for care that was not met was about 11 per cent. It was more likely for blue-collar workers to have unmet care needs (14 per cent) than for white-collar workers to do so (9 per cent). An analysis of the same question in 1996-99 shows that this inequality persists. Unskilled workers had more than twice the unfulfilled care needs of upper white-collar workers.

Apart from the differences between socio-economic groups there are also systematic differences between men's and women's health and consumption of care. Women live longer and consume more care than men do, but consider they have poorer subjective health and are more dissatisfied with care. In the databases that reflect shortcomings and problems in care, some 60 per cent of the cases concern female patients and 40 per cent male. Analyses of drug consumption show that women use more drugs than men regardless of drug group, while costs per prescribed drug are higher for men than for women. These circumstances suggest that there is every reason to continue with, and even intensify, the follow-up of equity and equal opportunity in care.

People with poorer economic circumstances and with worse dental health do not go to their dentists as often as those with good economy and good dental health, even though they have more need. However, the general dental health in Sweden is good.

1.1.3. Challenges

The total costs (in fixed prices) of the health services remained relatively constant during the 1990s. The costs for care staff excluding doctors and nurses decreased at the same time as drug costs increased. Starting in 1998 health services costs have increased. Despite this and despite increased production of care, e.g. more cataract operations and coronary interventions, the care debate has concerned problems in the health care. The main explanation to this is probably that developments in medical technology have brought ever-increasing possibilities to cure and alleviate disease states, including those among the growing numbers of old people, at the same time as the growth in resources has tailed off. Moreover, public demand has increased as have the ambitions of politicians and those responsible for the work. This has led to a growing gap between what is possible in terms of medicine and care and what is economically feasible.

At the same time there are signs that the resources of health care are not always being used in the best way: there is still room for increased efficiency. According to the Swedish National Board of Health and Welfare, treatment methods used in some parts of the services are actually without effect, are obsolete or are not evidence-based. Scrapping non-evidence-based methods of treatment is a matter of urgency both economically and medically.

Another area where more efficient care may be possible is the organisation of care, for example through better co-ordination between various authorities and care levels. In the work close to patients, *evidence-based medicine* has become a central concept which means that systematically compiled scientific knowledge should be used when deciding the treatment for individual patients. Similarly, decisions on structural and organisational solutions and care should be based, more than during the 1990s, upon scientific knowledge; on the consequences of alternative courses of action, i.e. on *evidence-based health care*. In practice, this means not carrying out organisational reforms on a large scale until their costs and effects have been analysed through scrutiny of corresponding changes elsewhere or through one's own trials.

A major problem in this connection, however, is the lack of overall information regarding the achievements, costs and quality of medical care since there is no over-arching follow-up of the work. This in itself is probably contributing to shortcomings in care efficiency.

In order to achieve high quality of medical care, also in the future, it may be necessary to increase the proportion of GDP allotted to medical care expenditure. How far this may go depends also on whether health care services can manage to exploit the scope for rationalisation when focusing

on evidence-based prevention, care and treatment. Another decisive factor is the extent to which financial and organisational problems in the health services, primarily the extensive shortcomings in co-ordination between care levels, principals and staff categories, will be dealt with.

1.1.4 Planned policy changes

From 1 of July 2002 there is a maximum fee for elderly patients resident in the municipalities. At the same time, a high-cost ceiling of dental care was introduced for the elderly.

The Swedish government will in the next coming years introduce a national care guarantee, where acceptable waiting times are defined.

In November 2000, the Swedish Parliament adopted an action plan for the development of health care. One of the aims with the action plan is that older persons shall receive better health care through better medical attention. Another aim is to improve and defining the task of primary care. Municipalities and county councils are to receive extra funding of SEK 9 billion between 2001 and 2004 for the development of the health care.

The county councils will also receive SEK 3,75 billion between 2001 and 2004 to improve the accessibility to the health care.

1.2 LONG-TERM CARE

1.2.1 Access to long-term care

The aims for the care of the elderly in Sweden is to guarantee a secure economy, good housing, and service and care according to needs. Public help shall allow freedom of choice and influence for the recipient and maintain high standards. The elderly shall have equal access to these welfare goods regardless of age, sex, ethnicity, place of residence, purchasing power.

In Sweden, the responsibility for the welfare of the elderly is divided between three principals or levels of government. At the national level, the Parliament and the Government set out policy aims and directives by means of legislation and economic steering measures. At the regional level, the county councils are responsible for the provision of health and medical care. Finally, at the local level, the (289) municipalities are legally obliged to meet the social service and housing needs of the elderly. Both the county

councils and the municipalities have a very high degree of autonomy vis-à-vis the central government. Both have elected assemblies and have the rights to levy taxes. The county councils and municipalities may, within the limits prescribed by the existing legislation, decide the degree of priority they will give the elderly over other groups.

In return for taxes, people are provided with a broad spectrum of welfare benefits that guarantee a minimum standard of living, service and care and redistribute income more evenly over lifetime and between individuals. The elderly's economic security is based on a basic old-age pension payable to everyone from the age of 65. The State also pays an income related supplementary pension financed from the employer payroll fees. The pension benefits are adjusted to inflation, and provide everybody with almost two thirds of former income. Therefore, in general, nobody has had to forgo service and care, due to economic reasons.

In 1992, to consolidate financial and care responsibilities it was decided that the responsibility for the care of the elderly should be borne by one level of local authority; the municipality. Then, the Community Care Reform (the Ädel reform) represents the main approach towards integrating health care and social services. The reform implies an extensive decentralisation of responsibility and resources from the regional to local governments.

- The municipalities were given the statutory responsibility for all types of institutional housing and care facilities for the elderly. That is, long-term care hospitals (geriatric clinics excluded), nursing homes, old-age homes, service houses, group homes and day care facilities.

- By agreement with the county councils, the municipalities can also take over the responsibility for home nursing care. However, the responsibility to provide health care, does not include medical care provided by physicians.

- The municipalities are financially responsible for all other types of long-term institutional care, which they do not operate. The responsibility also includes patients in somatic short-term hospital care (”bed-blockers") and in geriatric hospital care. The municipalities have to make payments to the county councils for elderly that stay at geriatric hospitals after the medical treatment is completed.

- The municipalities were also given the statutory responsibility to provide assistive devices according to the needs in the elderly population.

Sweden has an extensive system for service provision in elderly care. The most important services for making it possible for elderly to go on living in their own homes are home help services. This contains help with daily activities, e.g. shopping, cooking, cleaning and laundry. It also includes personal care such as help with bathing, to go to the toilet, getting dressed and in and out of bed. In 2001, about 7.9 per cent of the population (65 years and older), received home help services. Of these, about one third also received home nursing care. Of those aged 80 and older, 18 per cent of this age group, received home help (National Board of Health and Welfare, 2002). In summary; the number of people receiving home help, has constantly decreased in relation to population growth. However, the volume of service input (contact hours) has increased successively. In other words, fewer persons get more help (Agüro Torres et al.,1995; Sundström and Tortosa,1999).

Home help has been made available increasingly during weekend, evening and night hours. In 1988, 16 per cent of those with home help received it in the evenings and at night; in 1997 this had increased to 28 per cent. Besides home help, there is also a comprehensive range of municipal services for the elderly, such as transportation services, foot care, meals on wheels, security alarms, housing adaptations, disability support, etc.

The development in the area of special housing (institutional care) is quite similar to what has happened in the home help services. As a result of the Ädel reform, all types of institutional care have been gathered under one ”umbrella” heading; ”special housing” with service and care for elderly. This concept then comprises: nursing homes, old age homes, service houses, group homes etc. Until the early 1980s, institutional care expanded in pace with changes in the population. However, since then, this expansion has successively stagnated. In 2001, some 118 000 people were living in different forms of institutional care or in ”special housing” for the elderly in Sweden (National Board of Health and Welfare, 2002). This corresponds to a service coverage of 7.7 per cent of 65 years and older and more then 20 per cent among those 80 years and older.

Both the health care and social services are subsidised, with the recipient usually paying only a fraction of the actual cost. Charges vary among the municipalities. At the present, the fees (out-of-pocket costs) for health care and social services are increasing. But, to limit the cost for the recipient (for out-patient care), there exist a "high-cost-limit", which means that no one has to pay more than a total of 2 200 SEK per year for health care (including prescriptions), regardless of the type and amount of care received.

The fees for home help are related to how much help is needed and income. Again, the user pays only a fraction of the cost of providing the services. In mid 2002, a new law was enacted introducing a "floor and ceiling-system", regarding charging elderly for services. The law regulates the maximum level of charging (the ceiling) as well as the guaranteed amount (the floor) to be left, after the cost for housing, services and care is paid.

1.2.2 Assessment

Swedes have a statutory right to claim service and care whenever needing. But each municipality decides their own level of service, eligibility criteria and range of services provided. Elderly care provision is based on a single-entry system; the person in need for help turns to the municipality where he or she lives, to claim help. Need determination takes place through a process of need assessment, carried out by a municipal care manager.

The single individual could claim services but he/she has no automatic right or entitlement to services. If the elderly person requesting services is dissatisfied with the care manager's decision, the case can be appealed against in the administrative court. Data from a national representative study carried out in 2001, show that the number of appeals are residual. However, although the number of appeals is very low, the right to appeal is considered as an important individual protection.

The assessment usually starts with a home visit (or e.g. a meeting with the elderly at the hospital) for a review of the request and need for services. The process also includes discussions with the family and consultations with other professionals to collect necessary information and data. In more than half of all municipalities, care management is based on a purchaser – provider model. In those municipalities, another part of the organisation takes on the actual provision of services after the care manager has done the assessment and decided on what care package is needed. Private (for-profit) service providers could also be contracted. In the traditional care management system, the care manager is responsible both for the assessment and to organise the provision of help.

Recent reforms in service provision combined with a weaker economy in the 1990s have increased the importance (and highlighted the difficulties) of the care management in Sweden. Care managers have been given increased caseloads as well as increased responsibility as a result of the Ädel Reform. This has in turn promoted a specialisation in care management. In several municipalities nursing home placements have become the responsibility of a special care manager who is usually a nurse, based on the belief that decisions concerning the type of health care needed should be made by a professional with a background in health care.

In general, institutional care is usually not seen as an alternative, until every other alternative is exhausted. The main reason for moving to institutional care is cognitive impairment (i.e. dementia) especially if the person is living on his or her own. Due to the fact that the number of institutional beds/places have not expanded in pace with the demographic growth, an increasing number of municipalities now report waiting lines to institutional care.

The availability of care resources also varies greatly in different parts of the country. According to Berg and colleagues (1993), the proportion of elderly people 80+ receiving home help ranged from 17 to 80 per cent in different municipalities, while the utilisation of long-term institutional care and old age homes could range between 9 and 37 per cent. Further more, there are no evidence in support of the idea that a low utilisation (and supply) of institutional care is generally offset by an increased utilisation of home care (Trydegård, 1998).

1.2.3 Challenges

The 1960s and 1970s could be described as the era of expansion of elderly services in Sweden. Backed by a strong economy and political consensus, care of the elderly was given priority. Both the institutional and the home-based care expanded rapidly. However, starting in the late 1970s and continuing for a decade, this expansion was slowly halted and an era of stagnation began. The period from the late 1980s until the present could be characterised as an era of service contraction. For the elderly, there is a growing gap between resources and needs. In fact, service provision in terms of coverage ratio is dropping back in many municipalities. Despite this, 9 per cent of the municipalities increased their service level and a vast majority show an unchanged level of services (National Board of Health and Welfare, 2002).

The fact that formal services now are reaching a smaller number of elderly, point to the fact that families more often have to ”fill the gap” between service demands and formal provision. Other alternatives, e.g. to turn to the market and to buy the services you need (and want), are used by very few elderly, now as before.

1.2.4 Planned policy changes

At present there are no major policy changes planned in long term care for the elderly in Sweden. However, a National Action Plan for Development in Health Care in which improved health care for the elderly has been given priority, came into force 2001 and will end by the year 2004. The prime

motive for this plan is the recognised need to improve basic health care. Thereafter, to improve and develop primary health care, psychiatric care and health care for the elderly are the three major goals for the action plan. The construction of the plan is partly a block grant to the local authorities to enable them to expand and develop services in accordance with the goals pointed out by the national government, which in turn has been agreed on by the local authorities.

In July 2002, the Swedish government assigned to ten authorities the development of an action plan on how to recruit and keep personnel in the long term care for elderly and disabled people.

2 QUALITY

2.1 HEALTH CARE

2.1.1 National standards and patients' rights

According to the Swedish legislation, health care services shall be of good quality and given on equal terms to all people. The decentralisation of the Swedish health care system, including care for the elderly, gives the counties and municipalities a high degree of freedom in how to *structure* and *organise* the delivery of services on the local level. This diversity places high demands on national monitoring and supervision regarding the *accessibility* of care and *outcomes* of health care interventions. Following developments and monitoring activities regarding quality, safety and individual rights of the patients are central tasks for the National Board of Health and Welfare.

The 1997 Code of Statutes of the National Board of Health and Welfare states that continuous and systematic quality assurance and improvement shall be implemented in all medical and dental services. From 1998 a similar regulation concerning the care for the elderly has been in force. The Code also requires that health care institutions should regularly monitor the quality and results of their services and, when possible, present material for benchmarking and comparisons.

Since the middle of the 1990s the National Board of Health and Welfare has been producing national guidelines for the care of patients with serious chronic diseases that can lead to long-lasting disability or premature death if not treated. This work is directed at the group of diseases that claim a large proportion of health care expenditure. The guidelines contain recommendations for care and treatment and proposals for measurable quality indicators. To guarantee that the recommendations are based on sound scientific evidence, new guidelines are largely based on systematic

syntheses of the effectiveness and cost-effectiveness of health care interventions, compiled by the Swedish Council on Technology Assessment in Health Care.

The contents of the guidelines are kept up-to-date through periodic revision. At the time of writing, the Board has published national guidelines on the management diabetes mellitus, coronary disease and stroke. Their purpose is to:

- Provide bases for regional/local care programmes.
- Stimulate and facilitate quality assurance.
- Provide a basis for open decisions on setting priorities based on parliamentary decisions regarding health services priorities.

One intention of the recommendations for good medical practice expressed in the guidelines is that they shall form a basis for the Board's supervision of that activity. Hence, the guidelines can be viewed as an important part of the national norm establishment in Swedish health care.

The health services legislation in Sweden has emerged as part of administrative law and is based on a tradition of obligations incumbent on health care authorities and care staff, with few explicit rights for the patient. Patient rights' was an important medical care policy issue during the 1990s, and the health services legislation was amended on 1 January 1999 to strengthen the standing of the patient. The changes involved the following:

- Clarification of the county council obligation to organise primary care so that all residents within its area have access to, and can choose a fixed contact with, a doctor.
- Definition of the obligation to give information.
- Greater patient influence over the selection of treatment where there are several medically warranted treatment alternatives.
- Patients faced with difficult medical choices may in some situations be given a second opinion.
- A new law on patients' trust boards, where the boards' area of work has been extended to cover all publicly financed health services and certain social services, chiefly in old people's care.

2.1.2-1.3 Quality assessment and quality improvement

The National Board monitors and supervises the quality, safety and accessibility of health care, while the national responsibility for the assessment of efficacy, safety, and cost-effectiveness of health care technologies lies with the Swedish Council on Technology Assessment in Health Care.

The prerequisites for monitoring the quality of care are extraordinarily good in Sweden. Data from *national health data registers* - National Cancer Register, National Patient Register, Medical Register of Births and Causes of Death Register - at the Centre for Epidemiology at the National Board of Health and Welfare are used, e.g., to monitor health care utilisation patterns and trends in avoidable morbidity and mortality.

About 50 disease- and/or intervention specific *national quality registers* contain data about patient characteristics, interventions and outcomes of care, e.g. National Register for Intensive Cardiac Care, Swedish Register for Coronary Angiography and Coronary Angioplasty, National Stroke Register and National Diabetes Register. Each register is managed by a group of professionals usually located at one of Sweden's university hospitals. Participating centres send their data to the management group, which assembles the data, undertakes statistical analysis, and disseminates comparative material to the participating centres. The National Board of Health and Welfare and the Federation of County Councils, with the help from the Swedish Society of Medicine, form a reference group and provide financial support for the development of the registers.

One of the most important purposes of quality registers is to provide material for quality development and to help equalise the differences within the Swedish health services. This may concern differences in what is offered and in availability, or differences in clinical outcomes and long-term effects for patients. Compilation of register data enable individual departments to compare themselves with each other, and they can also make comparisons over time. Both approaches are important for continuous quality improvement. The outcomes of care may also be checked against national standards given in, e.g., national guidelines.

The National Board of Health and Welfare has investigated the possibilities of developing overall indicators to monitor the quality of health services, partly starting with the medical quality registers. The results were reported in the autumn of 2000 in "Overall Quality Indicators in the Health Services", which includes proposals for some 60 overall indicators of this nature. Guiding the selection of these indicators were requirements on relevance, validity, measurability, possibility of affecting the development of health care and interpretability /unambiguity.

Four aspects of health care quality were in focus: medical quality, availability, the patient's experience and good health for the whole population. Among areas selected were diabetes care, coronary care, care in rheumatoid arthritis, psychiatric care, cancer care, paediatric services, maternity care, obstetrics and gynaecology, and care of the demented. A review of available data sources showed that some of the areas were relatively well covered, indicating several possible quality indicators. On the other hand, there were also large and important areas where suitable databases and registers containing quality indicators were largely absent. The most important examples are psychiatry, primary care and paediatric

care. Most registers, both quality registers and others, focus on relatively technical data, while details of nursing and patient experience are so far uncommon.

2.1.4-1.5 Future challenges and tentative policy changes

A strategic question of great significance for the future of the Swedish health care system is the supply of staff in several profession categories in the health services. The number of specialists in general medicine will have to be increased if primary care is to be capable of serving as the basis of the health care system. Shortcomings in working environment, may contribute to difficulties in recruiting and keeping staff. The Swedish government will increase the number of students at medical schools with 25 per cent and the number of students at nursing schools with 30 per cent the next coming years.

The medical quality of care depends on staff being able to benefit from the increasingly rapid international development of knowledge. For this purpose, comprehensive and continual work is needed on systematic compilation of the benefits, risks and costs of different care measures. We must also ensure that, through training and information, the results are applied efficiently in everyday medical care. While the Swedish Council on Technology Assessment in Health Care, and to some extent the National Corporation of Swedish Pharmacies prepare syntheses of the scientific evidence for various care measures, the Board will strengthen its support for the introduction of evidence-based practice in care. This will be done chiefly through national guidelines development in new medical areas.

One intention is that the purchasers of care should request from providers an account of how the guidelines are used and the results of care as measured through the quality registers and other indicators.

For patients, the national guidelines imply concrete possibilities of gaining information on good, scientifically based care and treatment. Patients can already, via the Internet, obtain certain information regarding care queues and waiting times. The patients of the future, however, will demand more general information on the quality and safety of care to be able to make rational choices among various care providers. In the next few years, a great challenge for the health care services will be to produce easily accessible and comparable information on quality for consumers and professional groups alike.

A revision of the Code of Statutes dealing with quality assurance in health care is considered in order to support regular, transparent quality reviews targeted at different interest groups; health professionals, purchaser, planners, tax-payers, consumers etc.

2.2 LONG-TERM CARE

2.2.1 Standards

There are no general standards or regulations regarding quality of long-term care in Sweden. In the Social Service Act (1982), a new paragraph was enacted in 1998 requiring that “social services should have high quality and the authorities are requested to have manpower to ensure that”. In 1998, the National Board of Health and Welfare regulated that every municipality must have a system of quality assurance in service and care for the elderly.

The Social Service Act, is a so-called “frame law”, which implies that the individual has no declared rights, which he or she could claim. Then, it is up to the municipality to decide on (within the context of the law) eligible criteria and standard of services provided.

2.2.2 Monitoring and promotion of quality

In the area of long-term care for elderly, mainly two pieces of legislation apply. The Social Services Act (1982) emphasises the right of the individual to receive public service and help at all stages of life. Anyone who needs support in his or her day-to-day existence has the right to claim assistance if the 'needs can not be met in any other way'. In 1983 the Health and Medical Services Act came into force. According to this Act, health care and medical services aim to maintain a good standard of health among the entire population and to provide care on equal terms for all.

On the basis of current laws, monitoring and supervision of the services is carried out by two different authorities: Services based on the Social Services Act (i.e. most of the services provided by the municipalities) is monitored by The County Administrative Boards and health care is monitored by National Board of Health and Welfare. The division of responsibility has in recent years been repeatedly debated in Sweden and a call for a joint system for monitoring and supervision in elderly care has been suggested.

While the formal service system has been an important component of policy designed to help the elderly manage at home, there has been increasing awareness that most families provide some informal care and many older persons prefer informal care. Several studies have during the 1990s reaffirmed what is well known from other countries, that informal care plays a dominant role in care of the elderly. So far there is no evidence that the development of an extensive formal care system, as in Sweden, will impose

a decrease in informal care giving, rather the opposite (Johansson, 1991; Sundström, 1994; Herlitz, 1997; Johansson, 2000; Sundström et al., 2002).

During the 1990s, there has been a rapid growing interest in informal care and the role of the families. First, one of the major experiences in promoting home-based community care, was that home care is often dependent on extensive family care giving. Second, along with the economic recession, there is a growing interest in the informal care sector and its potential to substitute costly formal services. Third, in recent years there is also a growing body of research evidences, pointing to the crucial role of the care given by the family. Fourth, and most recently, the carers and their organisations are now more openly addressing the public care system for recognition and support.

For many years, support programmes for family caregivers have been available in Sweden. There are primarily three types of support: respite and relief services, support and educational groups for carers and economic support for caring. However, these programmes have been poorly targeted, with an uneven coverage and quality. During recent years, these problems have increasingly been recognised and in 1997, the Government directed extra funding to research- and developmental activities aiming at developing ”new models for supporting carers”. In the revised Social Service Act (1998), the Parliament introduced a new paragraph, urging the municipalities ”to support families when caring for elderly, disabled and long-term sick persons”. This new law is regarded as a new strong signal to the local authorities to address caregivers support.

In June 1998, the Swedish parliament decided on a National Action Plan on Policy for the Elderly, which came into power in 1999. Included in the Action Plan there was ”package” of increased state block grants to the local authorities in order to ”improve the conditions in schools and caring services”. The increased funding represent a permanent raise of the state grants to the local authorities. The ”special initiatives” launched by the government are also attached with a three years grant for financing of developmental work in areas that the government want to promote.

Among the initiatives that could be mentioned were special grants for in-service training, improved collaboration between care-providers, supervision/monitoring and evaluation, gerontology research, quality insurance activities, incentive grants for special housing for the elderly etc. Special state funding was also available for RoD-project regarding preventive health visits among the elderly. Another initiative was a renewed effort to stimulate caregiver support. During a three-year period of time (1999–2001) SEK 300 million of State grants was made available for the local authorities, in order to further develop supportive services for carers. Many of these state grants have been successful.

2.2.3 Challenges

The increasing problem to attract and recruit care personnel now challenges the caring services in Sweden. The problems relate to virtually all types of professions, from physicians to home-helpers and exist all over the country. This not a new problem, but seems to increase rapidly. The basic problem is that – even if you are granted a permanent job – care work in general and care work with elderly especially - is loosing its attraction.

The issue of quality in services and care for the elderly is directly and indirect affected by the manpower problem. Despite the manpower problem, no studies undertaken have shown any sizable number of elderly living in misery. Users of elderly care overall rate the quality of the care very high.

2.2.4 Planned policy changes

Given the challenge described above, the major issue today in long-term care is to secure a stable and sound manpower situation. Right now, there is an intensive debate on how and what should be done with these problems, and a number of measures are in view.

To act on the manpower problem, both national and local governments, together with the labour organisations are now discussing urgent initiatives, such increased salary, increased staff density, "on-the-job-training"-programmes and general improvements of working conditions for care workers in long-term care for the elderly.

3. Sustainability

3.1 HEALTH CARE

3.1.1. Expenditure and financing

The following figure shows how the health services are financed in Sweden by the state, the county councils the municipalities and by the patients.

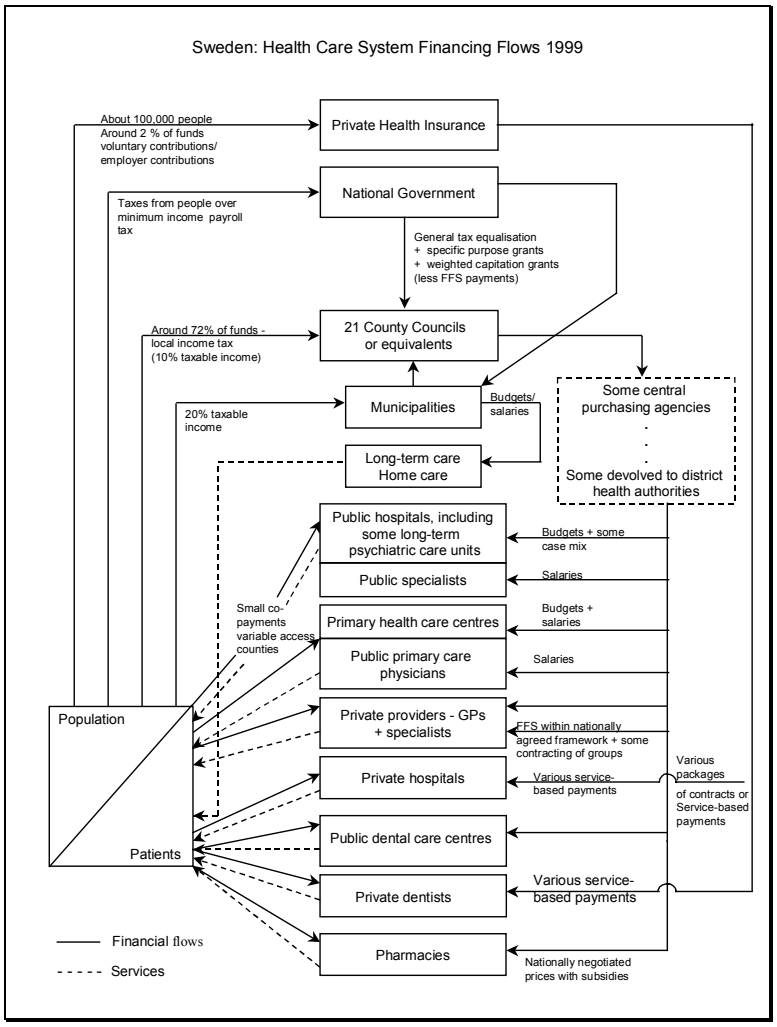


Figure. Health services financing in Sweden by the state, county councils and municipalities, and patients.

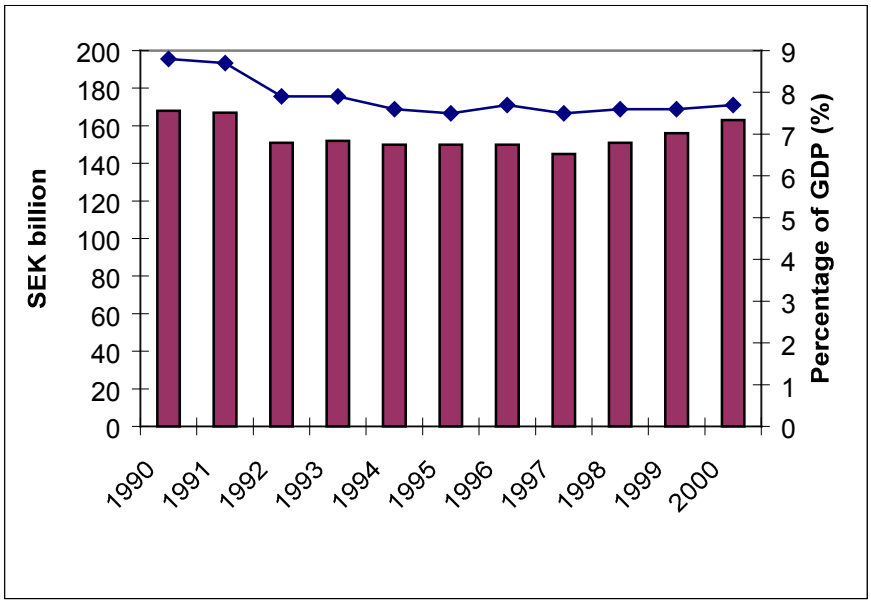
3.1.2 Expenditure trends

For the first time since the 1930s Sweden, at the beginning of the 1990s, suffered an economic recession with three consecutive years of decline. Serious imbalances in the form of increased national debt and unemployment led to further increased demands for rationalisation and cutbacks. That resources for the health services decreased in relation to those of other countries is probably an effect of the lower economic growth rate in Sweden than at the beginning of the 1970s.

At the beginning of the 1990s the economic recession led for the first time to a genuine cutback in health services resources in Sweden, in the form of numbers employed and hours worked (Statistics Sweden). Thanks to considerable increases in productivity, the volume of activity was largely maintained, with a shift from institutional care to out-patient care. Staff costs have decreased but this has largely been offset by strong increases in

pharmaceuticals costs. Pharmaceuticals represented 8.4 per cent of health care costs in 1990, increasing to 15.5 per cent in 1999. Staff decreases have concerned largely nursing auxiliaries and assistant nurses, while the numbers of doctors and nurses increased during the period.

Total costs for the health services in 2000 were SEK 163 billion, corresponding to 7.8 per cent of gross domestic product (GDP). The costs from 1990 onwards are shown in the figure below.



Health care expenditures in Sweden 1990-2000 in 2000 prices (left axis) and percentage of GDP (right axis). The costs for municipally financed care and nursing are not included

According to statistics a smaller proportion of GDP was used for health care in 2000 than at the beginning of the 1990s (7.8 per cent compared with 8.8 per cent). However, this is largely because of the Ädel reform under which, starting in 1992, primary municipalities were given combined responsibility for long-term service and care for elderly people and the disabled. In fixed prices the costs for the health services have been largely the same.

The National Board of Health and Welfare has calculated that approximately 15 per cent of total staff resources in municipally financed care and nursing are employed on health and health care tasks (National Board of Health and Welfare 2001a). On the basis of these figures, the proportion of municipally-financed health and health care is calculated to about SEK 14.6 billion, corresponding to 0.7 per cent of GDP. For a complete picture of the health services' proportion of GDP for 2000, the figure must be revised up from 7.8 per cent to 8.5 per cent, which tallies relatively well with the reported OECD comparisons of its member countries' health services costs.

Of county council net costs for 2000, 63 per cent went to somatic short-term care, 19 per cent to open primary care, 11 per cent to psychiatric care, 3 per cent to geriatric care and 4 per cent to other activities. Net costs for health and health care excluding dental care were, in 2000, SEK 11,896 per inhabitant, ranging from SEK 10,281 (Kronoberg county) to SEK 14,268 (Norrbotten county). Costs for county and regional health care averaged SEK 9,156 per inhabitant, with a variation from SEK 7,900 (Skåne) to SEK 11,001 (Norrbotten). Costs for primary care excluding dental care were SEK 2,740 per inhabitant with a spread from SEK 2,024 (Kronoberg) to SEK 3,813 (Dalarna).

3.1.3. Cost control mechanism

In Sweden we have a long tradition of fixed budgets as the primary instrument to control the costs. Since the early 1990s many county councils have experimented with a separation of purchaser and provider. There is some evidence that at least in the first half of the 1990s the counties with prospective hospital payment (e.g. DRGs) had a higher increase in productivity than counties with traditional fixed hospital budgets.

Patients can freely choose between health centres and hospital outpatient departments. One way in which county councils influence the decisions of patients is by charging patients different fees for services in health centres and hospital outpatient departments.

In the pharmaceutical care, there was a parliamentary decision that the county councils should take over the financial responsibility for drugs. One major reason for this reform was to make an incentive for the county councils to keep drug costs under control. Because of the high increase in drug cost, the responsibility is still shared between the national government and the county councils.

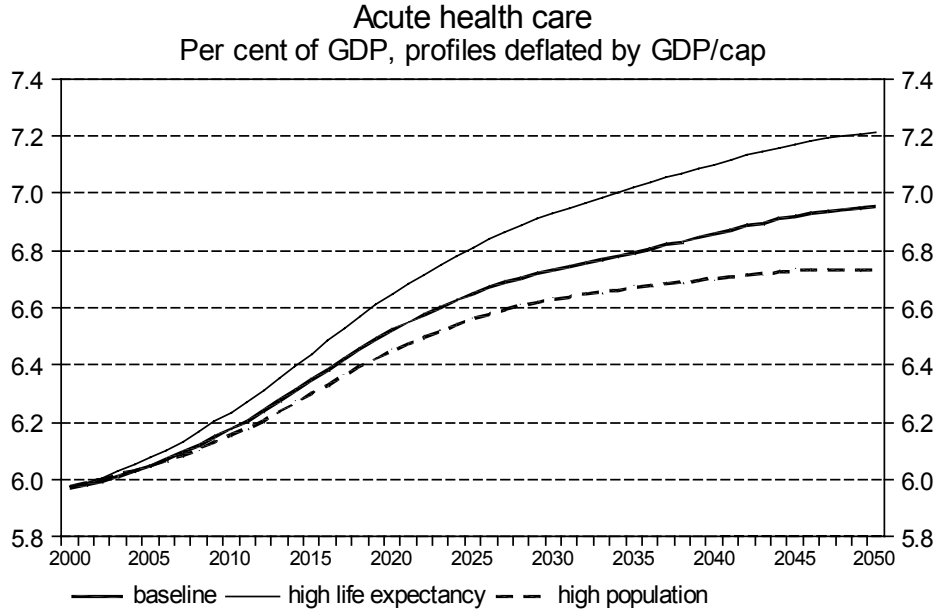
From the 1 of October 2002 a prescribed drug will in principal be exchanged for a generic drug with a lower price at the pharmacy. The Medical Products Agency determines which drugs should be considered generic and hence possible to exchange.

3.1.4 Challenges[1]

Sweden has projected the future trends of health care for the coming 50 years, published in the EKOFIN-report “Budgetary challenges posed by an

ageing population". Projections for Sweden show that the acute care expenditure for the total population will increase from about 6 per cent of GDP in 2000 to nearly 7 per cent year 2050 in the base line demographic scenario. Projections are also undertaken on two alternative demographic scenarios: high life expectancy population scenario and high population scenario. The high life expectancy population scenario means higher expenditure, 7.2 per cent of GDP the last projection year and high population scenario means lower expenditure, 6.7 per cent.

Figure 1



Several studies have shown that the last years in life imply the highest expenditures, irrespectively of how long people live. This means that projections of future health care costs should be projected years from death instead. Mårten Lagergren and Ilija Batljan have calculated future health care expenditure according to this method on Swedish data in the report "Will there be a helping hand?". Calculations presented in chapter 3 based on data from this study.

Future health care costs calculated years from death are presented in figure 2. Expenditure for acute health care is lower when death-related expenditure is taken into account compared to projections of expenditures by writing the average costs per age-group and sex forward. Instead of a total expenditure of 7 per cent of GDP year 2050 in the baseline scenario, the expenditure is 6.7 per cent of GDP.

A very important factor for the future health care cost is the increase of the standard in the health care sector. In this case, the unit cost is assumed to follow the increase of real GDP/capita.

Figure 2

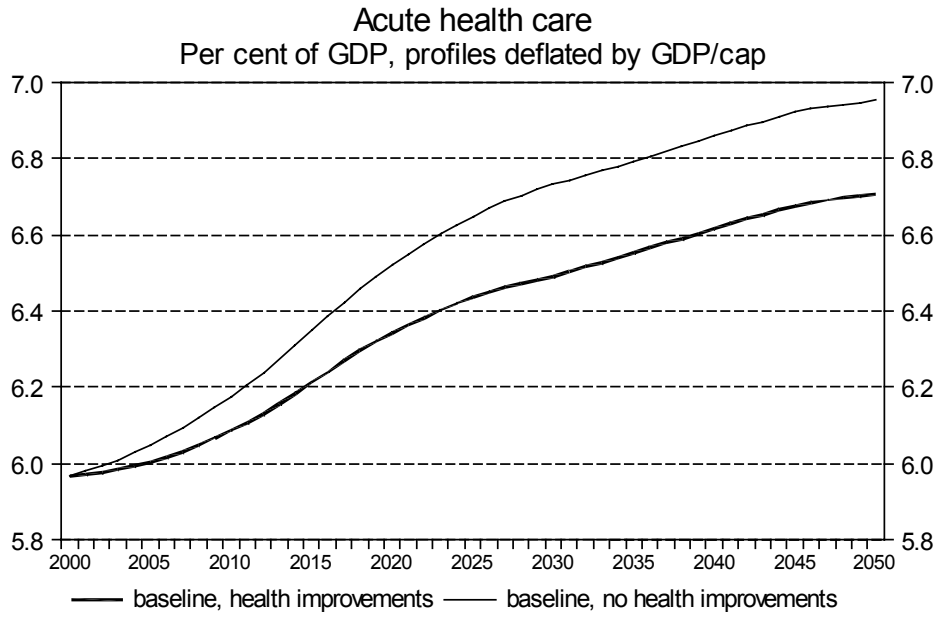
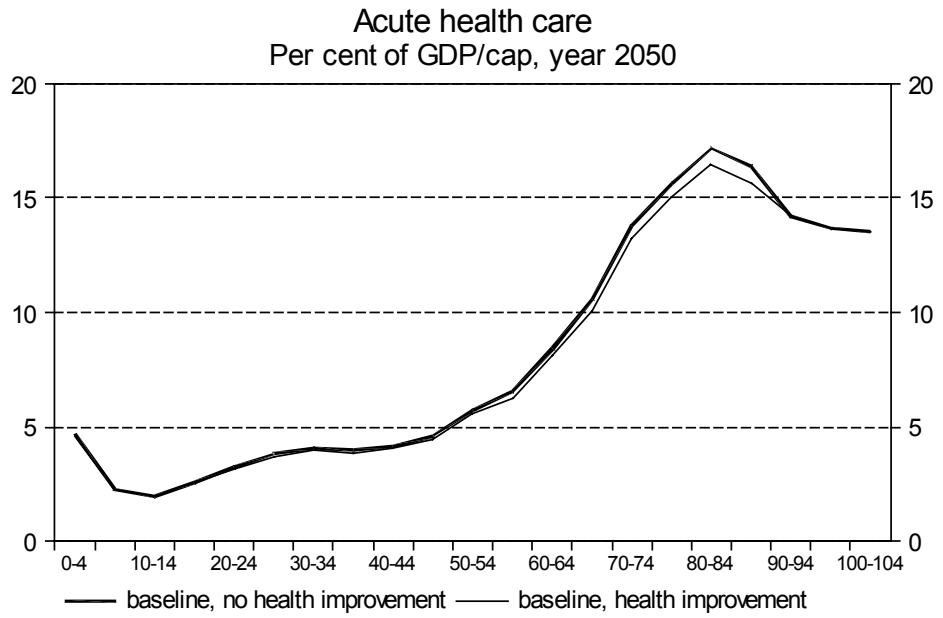


Figure 3 shows how expenditure is increasing over age. It starts to increase for age-group 50-54 years old, and reaches its peak for the age-group 80-84 years old. The numbers when we considered death-related expenditure are only slightly lower.

Figure 3



The demographic trend will subject the public welfare system to major strains, especially the health care and long-term care sector and the public pension system. In order to ensure the long-term sustainability of public finances, medium term fiscal policy focuses on maintaining a surplus in the general government sector of 2 per cent of GDP. General government net debt is thereby reduced. Net interest improves, providing scope for the anticipated increase in expenditure in the future.

3.1.5 Planned policy changes

After 1 October 2002, medicines and other medicinal products will only be included on then pharmaceutical benefit scheme if they fulfil the criteria set forth in a new law on pharmaceutical benefits. A new authority, the Pharmaceutical Benefits Board, will be responsible for determining if a drug or items covered by the pharmaceutical benefits scheme is to be subsidised. The agency will be in charge of reviewing all current medicinal products and determining whether the product will continue to be listed on the pharmaceutical benefits scheme.

3.2 LONG-TERM CARE

3.2.1 Expenditure and financing

The total public spending on social protection for the elderly – pensions, health care and social services - in Sweden, amounted to some SEK 300 billion or 14,4 per cent of GDP in 2000. The costs for health care and services for the elderly in 2000 was estimated at some SEK 142 billion or about 6,8 per cent of GPD. Most of this - two thirds - goes to various forms of institutional care, such as acute hospitals, nursing homes and old-age homes. The remaining third stands for outpatient health care and home help. Roughly 6-8 per cent of the cost refer to administrative costs.

Care of the elderly is almost totally financed by taxes. Only a fraction of the costs (5-8 per cent) is paid by the user. The largest share of the costs (about 82 – 85 per cent) is covered by local taxes. National taxes cover the remaining costs of elderly care (about 10 per cent). The fact that health care and social services for the elderly is primarily funded by local taxes, further confirm the independent role of the local governments versus the national government.

This is a rough overview of the financing of elderly care. However, the mix of contributions from the different sources of financing, often vary from one type of service programmes to another. From a tax-payer point of view, about 20 per cent of the (local) tax paid by on average work-income, is used by the local authorities to finance services and care for the elderly.

In some macroeconomic scenarios of future needs and costs of health and social care for the elderly in Sweden, Lagergren and Batljan (2000) present a more optimistic prognosis. Building on the actual improvements that are taken place in old people's health and mortality, Lagergren and Batljan argue that the projected care needs arrived at through extrapolations based

on the assumption of unchanged care needs for each age group are greatly exaggerated.

Instead, they conclude that if the current service level is to be retained, the rising number of elderly people will mean that public spending on elderly care and on health care will increase as a proportion of GDP over the next few decades. This increase will be sharpest in the 2010s for health care. For elderly care, the upturn will be delayed until the 2020s. These increases will be considerably larger if labour-force participation continues to decline. Further, assuming continued improvements in mortality and health among elderly people, these increases will be relatively moderate and less than half of that indicated by a simple demographic extrapolation. Up to the year 2015, the rise in spending on health and social care in relation to GDP will be insignificant. The increase during the years 2015–30 will be larger, but this is mainly due to the contraction of the labour force during this period.

With high labour-force participation and an unchanged service level, other public consumption as a proportion of GDP will fall over the next 20 years, owing to the smaller number of children. Owing to the decrease in the labour force, the proportion will then rise from 2020. If labour-force participation continues to fall, public consumption will have to continue to increase as a proportion of GDP throughout the period, if the current level of services is to be retained. High labour-force participation affords good scope for financing public welfare services successfully in the decades ahead. With declining participation, prospects are considerably less favourable.

3.2.2 Cost control mechanisms

The municipalities and the county councils have during the 1990s developed different strategies to secure the welfare of the elderly (Johansson, 1993). The traditional Swedish strategy, i.e. increase of taxes in order to finance the services, has been questioned. Even if, as certain survey indicate, many Swedes are willing to pay more taxes if they are assured that the money will be used to improve e.g. elderly care, this does not seem to be ”the solution” any longer. Moreover, there is at present political consensus that taxes cannot be raised further, and the government enforced a tax-ban for the municipalities. Since 1995 the government has urged the municipalities not to raise taxes and presently the government has set a goal for the municipalities to have balanced budgets by the year 2002. Squeezed between having fewer resources and increasing needs, the municipalities have been elaborated to find ways to reduce costs and/or increase cost effectiveness.

The most common strategy stands for various measures to *reduce labour costs*; the dominant part of the total costs in caring services. One example is to reduce staff density or to hold back salary increases or to employ care personnel by the hour.

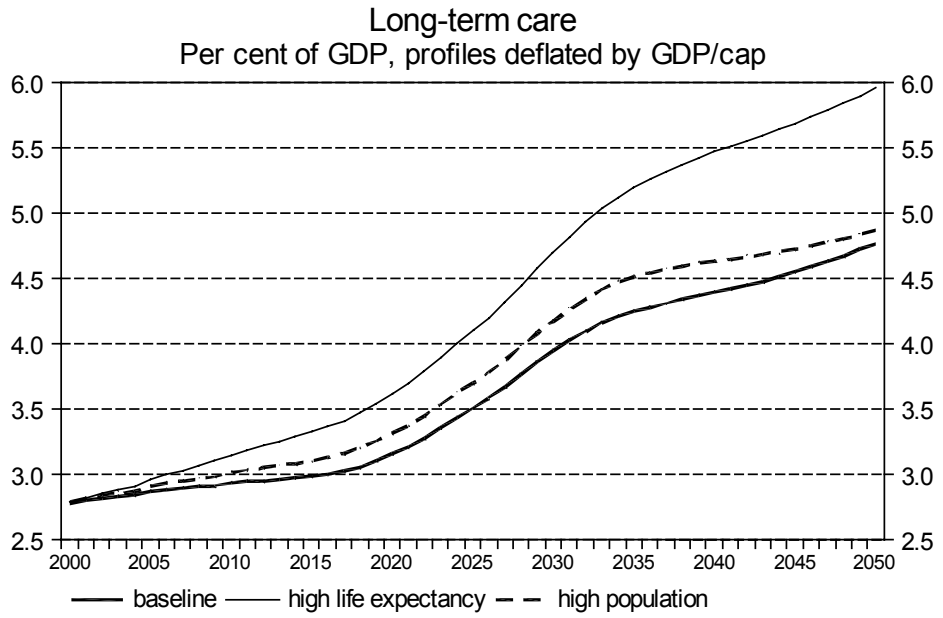
Many municipalities nowadays, has also *cut down on the level of services* and/or dismantled certain programs. Further, eligibility for services is changed in order to target the services to the most frail and needy. At the same time a greater share of the costs for services and care is shifted over to the individual user. The municipalities have been *increasing the fees* for services and reducing the subsidies as a means of decreasing their costs. However, as pointed out in section 1.2.1, a new law was enacted in mid 2002 introducing a "floor and ceiling-system", regarding charging elderly for services.

Recent development has created an opening – and a *market – for new actors (producers) of services and care*. Approximately 10 per cent (on average) of the care recipients today receive their help and services from private providers. To "open-up" the elderly care field for private providers is in fact promoted in many municipalities. However, the funding of care and services is also in these cases a public responsibility.

3.2.3 Challenges

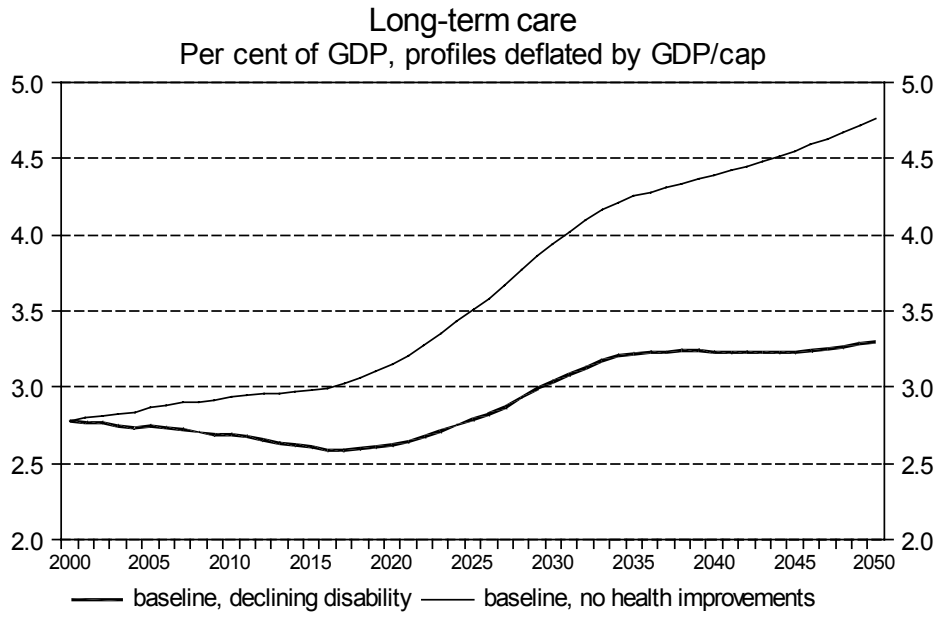
The main future challenge for the long-term care expenditure is the ageing population. Sweden has projected the future trends of long-term care for the coming 50 years, also published in the report "Budgetary challenges posed by an ageing population", and based on data from the report "Will there be a helping hand". The projection for Sweden shows that the long-term care expenditure will increase in the baseline scenario, from 2,8 per cent of GDP in year 2000 to 4,8 per cent of GDP in year 2050. The high life expectancy scenario gives an even higher increase to almost 6 per cent of GDP in year 2050.

Figure 4



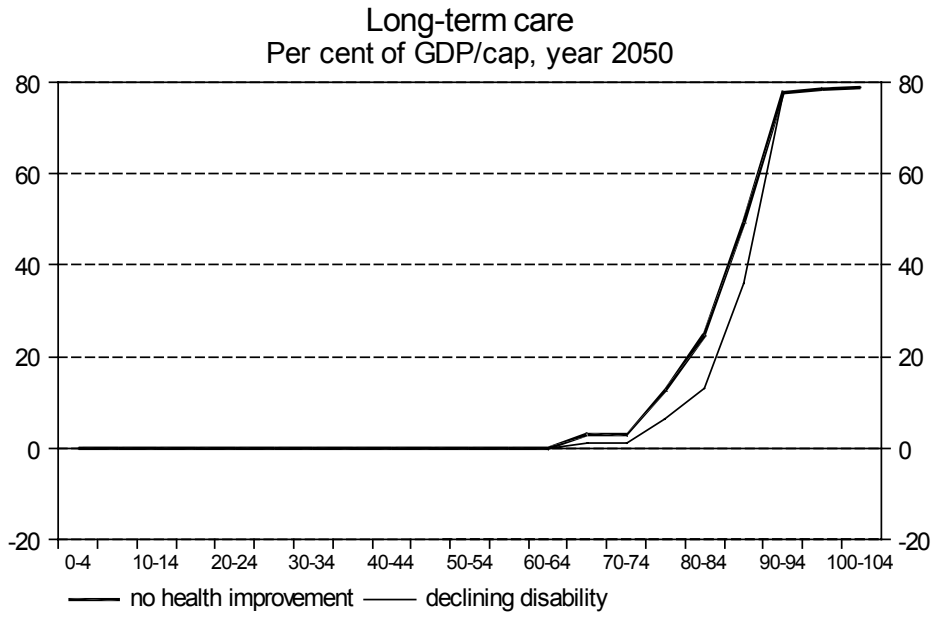
For the projections of future long-term care expenditure, Sweden has also undertaken projections on health improvements for elderly. Figure 5 shows that if health improvements with declining disability are included in the calculation, the expenditure for long-term care only increases to 3,3 per cent of GDP compared to 4,8 per cent of GDP, in the baseline scenario.

Figure 5



The age-related shift in profile due to the improved health effect is shown in Figure 6. The shift is strongest for age-groups from 65 to 90. After the age of 90 the long-term expenditure is the same due to restrictions in data.

Figure 6



Today and tomorrow, the issues of financing elderly care and to recruit care personnel, constitute an increasing challenge. The problems of financing elder care is actually a kind of ”welfare paradox”, i.e. due to improved general living conditions in Sweden, Swedes are living longer and reaching the age when service and care needs are mounting. This development puts pressure on the tax-based system of financing the welfare of the elderly.

Then, the process of change in health care and social services should be viewed in relation to the general development in Sweden. The dominant problem in Sweden during early 1990s was the economic recession, with historic high unemployment (almost 10 per cent of the labour force) and a large budget deficit. Increased unemployment also means increased costs for unemployment benefits and less tax revenues, and added problems to the difficulties to finance the provision of the services.

Thorslund and colleagues (1997) have pointed on that Sweden’s welfare state emerged during the prosperous years following the Second World War. The economy was flourishing and the political choices were a matter of which sectors of the society should be supported and expanded. However, today’s political choices consist of allocating resources that seldom suffice to fulfil the needs of the population. Difficult decisions must be made about which service sectors must reduce expenditure and which services must be discontinued. Then, the system of providing care for elderly people cannot be expected to continue unchanged in the face of the numerous changes occurring in society.

The most acute challenge in long term care for the elderly is the increasing manpower problem. There is a constant need to recruit large numbers of care

personnel to the long-term care services. Another problem is to maintain the care personnel that have been recruited.

An additional problem is an increasing numbers of care workers on long-term sick leave.

Present and future national policy on care for the elderly in Sweden is largely based on Lagergren and Batljan analyses. Their conclusions have also paved the way for a shift of focus in the public debate away from the need for a new system for financing long tem elderly care in the future. Instead, the major challenge for the future is the issue of sustaining a high level of labour-force participation in order to secure the economy and the welfare of the elderly.

3.2.4 Planned policy changes

Further actions have been taken in the beginning of 1999, when the Government appointed a parliamentary committee (”Senior 2005”), which is mandated to “to present proposals regarding the long-term development of elderly care in the future”. Probably, this will be a platform for future discussions about the structural problems in elderly care.

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