Quality of long-term care in residential facilities
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1 Background information

In Sweden, the responsibility for the care of the elderly rests with three authorities acting at different levels. At national level, the Swedish Parliament (Riksdagen) and the Government with its subsidiary agencies realise policy goals through legislation, supervision and financial control measures.

At regional level, the 20 county councils are responsible for the provision of health and medical care. At local level, Sweden’s 290 municipalities have a statutory duty to meet the social service and housing needs of the elderly. All municipalities are responsible for nursing care of the elderly and disabled people living in special housing whereas when it comes to health care for this group in their ordinary homes, more than half of the municipalities have that responsibility. In the rest of the municipalities the county councils are responsible. Care provided by medical doctors is always financed by the county councils. It is society’s duty to ensure that people in need of care or social services receive support of good quality.

Sweden has a long tradition of local self-determination. Local authorities are independent bodies, which are free to make their own decisions within certain limits. The legislation on social services, the Social Services Act, and on health care, the Health and Medical Services Act, allows the municipalities and the county councils very great freedom to plan and organise their own services and levy taxes in order to finance them.

The national authority – the National Board of Health and Welfare is responsible for supervision, follow-up and evaluation of municipal and county council caring services.

Over 18% of the Swedish population, or about 1.7 million people, are 65 years old or older. A great majority of the elderly (about 93% live in ordinary homes with or without home help services. More than 95,000 persons live in special housing. Nearly every fourth person or approximately 650,000 people aged 55 years and older is an informal carer.

2 National dialog

2.1 Challenges

Key issues on long-term care are the future economy, need for staff and to deliver health and social care of good quality.
Population projections show by 2035, the greater part of population growth will be in groups that are not of working age. By 2050 the proportion of elderly people in the population is expected to have increased from the present level of 18% to 25%. The very oldest part of the population has increased since the mid-20th century and the number of people aged over 80 is projected to almost double between now and 2060.

There is an ongoing debate in Sweden on care of the elderly and it has been dominated by care for the most frail older persons. Older persons with several simultaneous illnesses in need of care require specialised medical care as well as social services. One challenge is to find a system for co-operation.

With better health, the costs of care and social services per individual will decrease. The total costs will nevertheless increase, as there will be more elderly people. The costs of care for the elderly in the ageing population are expected to rise by around 70% and health-care costs by nearly 30% between now and 2050. The need for staff will increase by around 50%, most in care for the elderly, and a shortage of around 65,000 full-time equivalent staff is expected by 2030.

2.2 Interaction with stakeholders

The Government and the National Board of Health and Welfare each have developed different ways, depending on the targets, of interaction with the stakeholders involved, such as for example organisations for pensioners, next-of-kin’s or professional organisations involved. The Government has a dialogue with the Pensioners Advisory Council in matters concerning elderly issues. In most municipalities there is also a pensioners advisory council which gives advice in certain matters.

3. Quality assurance

3.1 Regulations

It is stipulated in the Social Services Act as well as in the Health and Medical Services Act that measures within social services and health care shall be of good quality. Suitably trained and experienced personnel shall be available to perform the tasks of the social welfare committee. The quality of activities shall be systematically and continuously developed and assured.

The National Board of Health and Welfare has regulated the significance of good quality.

National core ethical values for elderly care will come into force in the Social Services Act on the 1 January 2011. The regulation stipulates that older people should have the opportunity to lead a life with dignity. The Government will support municipalities to develop a system for local dignity guarantees. A dignity guarantee should be the performance promised to elderly people in need of care.

It is stipulated in the Social Services Act that every person active in caring services for older persons or persons with functional impairment shall verify that these persons receive good care and have secure living conditions. Whoever observes or becomes apprised of a serious abuse in the care of any individual shall report the matter immediately to the social welfare committee. If
the abuse is not rectified without delay, the committee shall report the matter to the supervisory authority. This also applies to professional private activity of a similar kind.

From 1 July 2011 the regulation will comprise all activities of the social services. It will be more obvious that it will be an integrated part of the municipalities’ systematic work with quality which is a duty for the municipalities.

3.2 Supervision
The National Board of Health and Welfare is responsible for supervising the activities of the LTC. The Board uses enforcement to tackle problems in health and social care - problems that should not exist. The review takes in consideration if people are given the health and social care they need ensuring good quality. The focus is on identifying gaps in activities, not to look for scapegoats and punish staff that has made mistakes. Health and social care needs to develop systems and procedures that prevent people from being exposed to risks and abuses as a result of staff error. In some cases, supervising individual health care professionals such as prescribing drugs in an unsafe manner or who because of illness or addiction can be a danger to patient safety. The National Board of Health and Welfare publishes a report on the outcome of supervision.

3.3 Open comparisons
In 2007, the Government commissioned the National Board of Health and Welfare to develop a system for open comparisons in care of older people consisting of a set of national quality indicators and the result of national user surveys. The aim of the system for open comparisons is to make it possible for everybody to compare the quality, costs and efficiency of the services provided to older people. Potential users, users, families, care personnel, managers, private and public providers and local and national politicians should all have easy access to comparative data about service and care. This could be the base for the older person’s choice of provider, support improvement efforts and form a basis for local and national monitoring, follow up and evaluation of services and care. Transparent reporting and comparisons has had a great impact and is increasingly being used as a basis for the work of improving health and social care. Today, there is a national website with comparable data from all municipalities and providers of home care and special housing, both public and private. See below, for further information under the headline Quality indicators.

3.4 User’s satisfaction
The objective of user surveys is to study the quality of home-help services and special housing from a user perspective. The User Survey 2008 was the first national survey that covers all municipalities in Sweden. The survey was based on two postal questionnaires, addressing recipients of home-help services and residents in special housing.

The results regarding the home-help services (in a national perspective), indicates that users rate the home-help services positively. The staff’s treatment of the elderly, the extent of the help and
the personal care measures, receive the highest ratings. Users of home-help services are less satisfied with information, food and social interaction and activities.

The quality factors that the users in special housing are less satisfied with are information, food and social interaction and activities. They are unsatisfied with not receiving help with the activities they want to spend time on. They are also unsatisfied with it being difficult to have a moment to talk with the staff or receive help from the staff to take a walk, when they want. The quality of the information from the staff is also rated relatively low when it comes to areas such as staff changes, changed times for help or hospital visits.

The results from the residents in special housing should be viewed in light of the fact that a large majority of those who answered the survey questions were family members. Many users are in poor health and have diminished cognitive functional capacity. Given the known difficulties in gathering users’ opinions, one can nonetheless confirm that the quality aspects that receive the highest and lowest ratings are practically the same among users of home-help services and in special housing.

4 Quality management

Traditionally 85% of Swedish care for the elderly is run by the municipalities. The rest has been awarded mainly to large corporations who have won public procurements bids for certain areas at a certain price for a certain period of time. Home help services and special housing can be run both by the municipalities and by private health care and social care providers such as companies, trusts or cooperatives. The funding and supervision of elderly care are municipal responsibilities, regardless of whether the services are run by the municipality itself or by private health care and social care providers.

4.1 Incentive grants

Incentive grants are available to municipalities and county councils to improve the quality of elderly care. Over the last four years the Government has allocated over SEK 4,000 million to improve the quality of care for the elderly. Seven areas were prioritised: better access to doctors in ordinary as well as special housing, medication reviews, preventive work, dementia care, rehabilitation, diet and nutrition and the social content. The National Board of Health and Welfare is responsible to follow up and assess if the quality of the care has increased in these areas. In the coming years the commitment will continue.

4.2 Freedom of choice

The Government is striving towards increased freedom of choice for the elderly and people with disabilities regarding provider of social, health and medical care support and services. January 1st 2009 a new law came into force (Law on System of Choice in the Public Sector). The law is voluntary for municipalities to use in organising the provision of social services but compulsory for county councils to use in primary health care. The aim of the new legislation is to empower those in need of social services and their relatives and increase their self-determination
4.3 Quality indicators and development

To present the results of the national indicators the National Board of Health and Welfare prioritised the development of an Elderly Guide. The Elderly Guide is a website on the Internet that is primarily addressing older people and their families. The guide contains information through 36 indicators about the quality of elderly care for all municipalities. It also contains quality data for individual units of special housing, home-help services and day care services. The quality dimensions used in the Elderly Guide are: accessibility, users’ involvement, staffing, training and continuity of care personnel, users’ independence, food, support for families giving care, physician’s involvement, preventive nursing care and services, management, follow-up and information about the services and care. The information is searchable in various ways and can be presented in tables, diagrams or as an overall report. The visitors can themselves choose which municipalities or units to compare.

The objective of the Elderly Guide is to provide overall information and a possibility of comparing municipalities and units of special housing. To obtain in-depth information about services and care, one is recommended to contact the municipality or unit in question, and links are provided. The information in the Elderly Guide is mainly gathered from special surveys and to a lesser extent processed from register data. The ratings in the Elderly Guide shed light on process and structural quality. The Elderly Guide is updated once a year. User studies show that the Elderly Guide is visited by some 300 people per day.

The National Board of Health and Welfare is working to develop the availability of data to present information about the facilities in LTC, as well as in other areas. This is to describe the needs of the elderly and the actions taken on those grounds. In order to be comparable, different data sources require uniform, clear and comparable concepts, terminology and classifications. The National Board of Health and Welfare has developed a model for needs assessment, using an international classification, International Classification of Functioning, Disability and Health, ICF, which is published by the WHO. The overarching goal is to provide a structure and a standardized language to describe functioning and disability in relation to health. Using the language makes it possible to retrieve information on activities via existing documentation.

5 Training measures

To enhance the quality of elderly care it is necessary that people working in health and social care services are professionally trained. The vocational skills of the staff are of great significance for elderly people in need of health and social care, particularly the many frail people who find it difficult to speak for themselves. The municipalities and county councils have the responsibility for the staff having requisite skills. Incentive state grants will be available to local authorities in the
coming years to educate managers and needs assessors when it comes to leadership and the regulation in the Social Services Act about the national dignity for older people.

In accordance with a regulation issued by the National Board of Health and Welfare of the personnel involved in handling cases related to older people, needs assessors, should have a university degree in sociology or social care. Knowledge in the following areas is highlighted: about aging and health, investigation and decision-making, relationships and attitudes, collaboration and coordination and the existing regulatory and legal developments. Continuous training and retraining are necessary components.

Today there is a lack of educated staff both physicians with geriatric competence as well as home carers and assistant nurses. The number of staff who has fundamental knowledge has although increased during the last years. The Government has commissioned the National Board of Health and Welfare to develop a system for basic as well as specialised knowledge for home carers and assistant nurses.

The National Board of Health and Welfare has developed guidelines for care in dementia along with stakeholders. The guidelines require the development of dementia care, including in respect of knowledge to make dementia studies and to develop methods of work to achieve a good dementia care. The guidelines are now being implemented in Sweden.

The Swedish Dementia Centre and the Competence Centre for relatives are non-profit organisations which are financed by the government. Their commission is for example to develop more practically orientated knowledge, facilitate translation of research and implementation of new knowledge into nursing and care, interventions and social policy, be a link between research, practice and decision makers and be the hub of a national network for research and development units.

Different ways of systematic development are being carried out by the employers in the municipalities and county councils, as well as by private organisations in charge of caring for the elderly. The regulations on management systems for quality and patient safety in health care and for quality in social care published by the National Board of Health and Welfare, have directions for the systematic quality work, the distribution of the responsibility, fields that are to be included and demands on routines for self-monitoring, follow-up and feed-back on experiences. Guiding principles to these regulations have been issued to facilitate and stimulate systematic work on quality. The need to combine knowledge for improvement with professional knowledge is emphasised.

6. Future role of residential care facilities

According to the Social Services Act, municipalities must set up special forms of accommodation for service and care of older persons in need of particular support. These special forms of accommodation for service and care include those previously known as old people’s homes, service flats for older people, sheltered housing (supervised shared residential accommodation) and the nursing homes which were transferred to local authority control from the county councils in conjunction with the reforms in the care of the elderly, ‘Adelreformen’ of 1992.
The individuals needs for long-term care or support in daily life is since 1992 no longer an assignment for the county councils and the hospitals. The municipalities are responsible for persons with needs that do not require the resources that only a hospital can provide. If a municipality fail in providing the help needed to ensure that the individual can go back home after a hospital stay the municipality must pay the hospital the daily cost for keeping the individual in the hospital longer than needed.

The housing conditions of older people do not differ significantly from those of the population as a whole; the general standard of housing is high. The construction principles for Residential care homes or Special housing follow the same rules and guidelines as any kind of housing. This means that each individual flat must be designed to meet the requirements of normal daily life standard. The municipalities are responsible for financing and provision of elderly care and will hence have the initiative in quality issues.

Since 1992 most older nursing homes have been modernised or replaced with modern units with acceptable standard. The different governments have periodically supported this process financially with investment grants. Today it is less than 0.5% of the more than 95,000 persons living permanently in special housing that must share room with anyone else than their spouse etc. The investment grant for special housing has now been in place since 2007 and have contributed to the reduction of the shortage in special housing. In the next budget the government will focus on a broader scope for supporting processes concerning housing for the elderly. The policy for the next four years will aim to bridge the gap between the point where you feel that it is no longer possible to continue to live in your recent home and the point where your needs are so extensive that a needs assessment will result in moving to special housing.