RESPONDING TO THE ELDERLY

security
self-determination

English summary

Final report by the
Commission on response to the elderly

SOU 1997:170

RESPONDING TO THE ELDERLY

security
self-determination
dignity

English summary

Final report by the
Commission on response to the elderly

SOU 1997:170

Government Official Reports
1997:170
Ministry of Health and Social Affairs

Responding to the elderly

security
self-determination
dignity

English summary

Utredningen om bemötande av äldre

Final report by the
Commission on response to the elderly
Stockholm 1997

This report is on sale in Stockholm at Fritzes Bookshop, which supplies Swedish official government reports and departmental series (SOU and Ds) and also, on behalf of the Central Services Office for the Ministries, arranges for them to be circulated to the competent parties for comments.

Address: Fritzes, Customer Services
SE–106 47 Stockholm
Sweden

Telefax: 08–690 91 91 (national)
+46 8 690 91 91 (international)

Telephone: 08–690 91 90 (national)
+46 8 690 91 90 (international)

E-mail: fritzes.order@liber.se
Internet: www.fritzes.se

Translation: Roger G. Tanner

NORSTEDTS TRYCKERI AB
Stockholm 1997

ISBN 91-38-20807-5
ISSN 0375-250X

Contents

English summary: Responding to the elderly

Chapter 1: Remit, working methods etc. 3

Publications from the inquiry....5

Chapter 2: Basic principles for developing a good response to older persons....10

Deliberate choice of basic approach 10
Reflections from others....11
Of power and knowledge....12
Continuing development - some examples....13

Chapter 3: Some perspectives on the situation of older persons, the conditions of ageing and the development of elderly care 13

Economic circumstances, housing etc. 14
Family and immediate surroundings - care by next-of-kin....16

Chapter 4: Response in caring services and other public activity....17

The development of caring services for older people....18
Response in different environments and in "other public sector activity" 19

Chapter 5: Personal support 20

Chapter 6: Response to next-of-kin etc. 21

Chapter 7: Of caring personnel....22

The working situation for personnel 24

Chapter 8: Supervision, disciplinary questions, secrecy and fact monitoring etc. 25

Chapter 9: Deliberations and proposals 26

Introduction 26
Supervision of caring services for the elderly 27
Wider responsibility for municipal health care and medical personnel 28
Higher level of training for handling officers and supervisory staff 29
The "Knowledge Lift" for established employees 30
Home nursing 30
The advisory boards 31
Contact person and guardian 31
Individual plan 32
Daytime activities, short-term care etc. 33
Support through personal assistance 33
A common structure for knowledge monitoring 34
Need for a research strategy 35
Use of quasi-coercive methods 35

Chapter 10: Consequences of my proposals 36

1 English summary: Responding to the elderly

By Government resolution in December 1995, Municipal Commissioner Britta Rundström, Helsingborg, was appointed, as special investigator, to chart and analyse questions concerning treatment accorded to elderly persons. Representatives of pensioners' organisations, trade union organisations, research and educational institutions, the two national associations of regional and local authorities, the National Board of Health and Welfare and the Ministry of Health and Social Affairs were appointed as special advisers. The special investigator set up a reference group comprising representatives of the organisations of the disabled.

The following is a short summary of the final report *Bemötandet av äldre (SOU 1997:170).*

Chapter 1:

Remit, working methods etc.

By way of guidance, the terms of reference for the inquiry emphasised that the time has now come to highlight the content and quality of caring services for the elderly, together with questions concerning response and respect for elderly persons' self-determination, integrity, security and dignity.

Response to the elderly can be affected by a number of factors on the part of the individuals concerned, but also in their surroundings. These "outward" factors may, for example, concern

†1 17-1642

laws and regulations, the structure and organisation of activities, physical design of housing accommodation or preconditions connected with the educational background and competence of personnel and supervisory staff.

My remit has been to chart and analyse shortcomings of response, ranging from almost imperceptible but deeply felt affronts to palpable abuses. I then proceed to recommend measures which can help to remedy deficiencies and abuses in the response to the elderly. In the course of this work I shall describe and benefit from the comprehensive work in which municipalities and county councils are engaged with a view to developing the quality and content of caring services. My working approach will be an open one and will encourage debate.

As part of my mapping work, I arranged a number of *colloquies* on question concerning response to the elderly, and I had useful discussions with representatives of the following organisations, authorities etc.:

- Associations of next-of-kin
- Students and teachers at a college of health and caring sciences
- Union organisations
- Disciplinary boards
- Organisations of the disabled
- The Health and Medical Advisory Board of the Federation of County Councils
- County Administrative Boards
- Pensioners' organisations
- Regional supervisory authorities of the National Board of Health and Welfare
- The Social Affairs Advisory Panel of the Swedish Association of Local Authorities

There is universal commitment to the necessity of creating conditions for *individual response to the elderly*. Important tools for this purpose, according to the colloquies, include firmly accepted policy objectives, competence development and the creation of articulate leadership at the workplace.

I also arranged a number of *roundtable talks*, for penetrating certain questions in greater depth. The aim here was to return, within a smaller circle, to experience from the colloquies and from the best practices communicated to the inquiry. In these talks, heads of elderly caring services, supervisory personnel, representatives of NGOs, relatives and others inspired several of

the proposals put forward in this final report. In certain cases I supplemented talks by means of field trips and separate deliberations with various interested parties, such as pensioners and nursing assistants/assistant nurses.

All through the inquiry I have been in close touch with individuals, relatives and personnel. Summing up, I have found great involvement with these questions, while at the same time finding that media coverage is hard to come by in situations where response and content generally are of good quality.

So far during the inquiry I have arranged for the publication of two interim reports and three reports; a further report (on various next-of-kin situations) will be appearing in close conjunction with this final report. Also, in collaboration with the National Board of Health and Welfare, I have commissioned a study of personnel training etc. The findings have been presented in a series of reports published by the National Board of Health and Welfare. In more rudimentary - stencil - form I have conveyed information on current development work in municipalities and counties and on comments received on the interim report concerning efficiencies of care and the report on best practices (see below). That material combines with the final report to convey various pictures of response to the elderly. Material from the investigation has been consistently transferred to cassette, Braille and easy-reader summaries, to enable persons with various functional impairments to take part in the general debate.

Publications from the inquiry

"Right to Move - a question of response to the elderly" (SOU 1996:161)

I presented this interim report in the autumn of 1996. It dealt with the difficulties occurring in certain quarters when older persons requiring a great deal of care and attention wanted to move to another municipality.

Although, quantitatively speaking, this was a small problem in the national perspective, I found that in each individual situation it entailed considerable inconvenience and put obstacles in the way of achieving the objectives of elderly care, respect for self-determination, integrity, security and dignity. In my opinion, the recommendations issued (by the Swedish Association of Local Authorities and the Federation of County Councils in 1989) did

not imply sufficient support for individual persons and their next-of-kin.

I proposed the incorporation of a new regulatory provision in the Social Services Act, entitling an individual person wishing to move to another municipality to receive support under Section 6 of the Social Services Act from the receiving municipality and to be treated on the same terms as persons already living there. It must be the duty of the receiving municipality to examine the entitlement to assistance of a person who is permanently in great need of care and attention or permanently in need of such measures. Following minor modifications of the proposal after the report had been circulated for comment, the Riksdag (parliament) resolved on the incorporation in the Social Services Act of a statutory provision, effective from 1st January 1998.

"Deficiencies of care - a question of response to the elderly" (SOU 1997:51)

As part of my remit I have charted and analysed shortcomings in the response given to the elderly. The terms of reference for the inquiry indicate the various sources of information which I have used.

Deficiencies of response, quality and content in activities relating to health and medical care are documented by county council disciplinary boards, the Health Services Disciplinary Board (HSAN), Patient Insurance and the Risk Database (RDB) at the National Board of Health and Welfare. Particulars of incoming complaints are systematically stored in databases. Social services do not have any systematic documentation of this kind. My knowledge of deficiencies and development tendencies in social services have been obtained through follow-ups and activity audits by the supervisory authorities.

I found that deficiencies of response were seldom the main reason for a complaint, but usually appeared after further analysis. The number of complaints to authorities etc. is small compared with contacts between the general public and caring services, and especially where persons aged 65 and over are concerned. There is probably a considerable "dark figure", although many complaints are cleared up within the activities concerned.

Complaints are usually made by next-of-kin or others close to the person concerned, not infrequently after the person who has been exposed to the deficiency in some way has died. Complaints

often concern persons of very advanced age who are in great need of care and attention and have limited possibilities of speaking for themselves. Deficiencies of information, dialogue and co-operation with the individual and next-of-kin are common causes of complaint, as are deficiencies of nursing, supervision and treatment.

All in all, the mapping and analysis led me to identify a number of fields in which I feel that several improvements are called for:

- the position of individuals and next-of-kin in the caring context,
- preventive measures, e.g. through personnel training,
- intensified supervision.

This final report shows that the process of change is a matter of both short-term and long-term action: certain quite unacceptable conditions will have to be changed quickly, while other changes involve, for example, training measures, which will continuously generate improvements and prerequisites of good response.

I also note that, certain grave shortcomings notwithstanding, a great deal of dedicated and highly skilled work is being done in the care of the elderly.

"Care with skill and empathy - a question of response to the elderly" (SOU 1997:52)

To enable me - in keeping with my remit - to describe work in progress in municipalities and county councils on matters concerning quality development and development of the content of care, I addressed a questionnaire to all municipalities and county councils in Sweden. The response was massive. Many municipalities and county councils sent in several examples of projects and development schemes. These span a wide variety of fields, such as the elderly and their situation, next-of-kin, personnel training and other ways of enhancing professional skills, strategies for quality development and so on.

In a special report whose title forms the heading of this section, I collected, with the assistance of journalist Charlotte Säfström, Skurup, a number of best practices from different parts of the country, my purpose being to show everyday work in elderly caring services where knowledge and empathy create

preparedness for change. One thing which all these examples have in common is that they describe the consideration and the capacity which develop when people derive strength from each other. This applies to elderly persons, next-of-kin and personnel. The interim report and this report were informally circulated for comment, to encourage discussion and suggestions. A summary of the results has been appended to the final report.

"Immigrants in caring services - a question of response to the elderly"(SOU 1997:76)

As part of my response mapping, I commissioned a number of researchers in the Research and Development Unit of the Stockholm Resource Administration for Schools and Social Services (D. Gaunt, F. Hajighasemi, K. Heikkilä) to illuminate the situation of older immigrants in their encounters with Swedish caring services.

Altogether Sweden has about 110,000 older inhabitants who were born in other countries. They are usually referred to as "older immigrants", regardless of when and how they came to Sweden.

"Older immigrants" are under-represented both among those receiving home help services and those living in special accommodation. The researchers enquired concerning the role of culture and response in the low utilisation of public caring services. To answer this and similar questions connected with response, two nationwide studies were conducted, one of them through a questionnaire and the other through comprehensive personal interviews.

The "older immigrants" proved on the whole to be satisfied with the response they had met with in caring services. There is criticism on individual points of detail, and this is very similar to viewpoints presented in other connections by older persons who were born in Sweden.

The report ends with a number of recommendations on planning the provision of caring services. The researchers note that older immigrants must be responded to individually: some of them desire separate arrangements - such as special accommodation together with others who speak their language - while others attach no particular value to arrangements of this kind. Outreach activities are advocated.

"Children's images of ageing - a question of response to the elderly" (SOU 1997:147)

There are many clichés about children's thoughts concerning older people, ageing and old age, just as there are about children's contacts with older people.

Through journalist Charlotte Säfström, Skurup, I arranged for interviews to be conducted with about 50 children between the ages of seven and 12, living in different surroundings and in different parts of Sweden.

The children show their opinions in interviews and drawings. Most of them, happy to record, are in close touch with older relatives. The report conveys insights into the children's conception of their own old age, of illness and death etc. In this report, with the UN Year of Older Persons, 1999, approaching, I wish to follow up ideas which were raised in the previous Year of Older People (1993), when one important theme was that of *Solidarity between Generations.*

"Respectful treatment - can it be taught?" (SoS-rapport 1997:17)

This report describes an interview study commissioned by the Commission on Response to Older Persons and part-financed together with the National Board of Health and Welfare. The purpose of the study was to investigate how personnel in elderly care acquire competence for responding to older persons through training and how that competence is then used professionally. Subjective personnel experience of theoretical training, practical training and professional activity form the theme of these personal interviews.

Response aspects had not occupied a prominent position in the theoretical training during periods of practical training. This was especially true in high school ("upper secondary school"). Graduates felt that somewhat more attention had been paid to response aspects, above all in a supervisory perspective, i.e. in relation to rank and file. Insufficient attention was paid to the integration of theory and practice.

The conclusion reached in the report is that both the content and form of different training programmes need to be reviewed. The need for in-service training and guidance must also be taken

into consideration at all organisational levels in caring services for the elderly.

Chapter 2:

Basic principles for developing a good response to older persons

Deliberate choice of basic approach

In this chapter I describe the basic principles of elderly care: respect for self-determination, privacy, security and dignity.

I find that the 1990s, through reforming processes such as the Ädel Reform, have created new opportunities for realising the guiding principles, but that much remains to be done. The time elapsing since the Ädel Reform took effect (in 1992) has also generated knowledge and experience which point to both advantages and disadvantages as a reason for ongoing change.

In spite of obstacles - such as the previously very parlous state of national government finance - many good initiatives have been taken and *are being taken* in Swedish elderly care. I am as anxious to highlight this aspect of elderly care as I am appalled by completely unacceptable situations which I also came across while the inquiry was in progress. The latter must be remedied without delay. But I would like to see the positive examples being given the coverage they deserve in public debate and the media. Examples of that kind are needed for the continuing process of change.

It is perfectly clear that development cannot be brought about solely by means of ad hoc action, necessary as this may be in certain situations, nor by projects - however good they may be - which are concluded without having any impact on day-to-day work. The development of good content in caring services for the elderly is a matter of processes which must involve many people within and outside the activities of elderly care.

One process which I have found to be superior to and more important than all the others and which I have therefore touched on several times in publications from this inquiry is the process which can lead to the basic principles being realised in the everyday context.

Respect for self-determination, privacy, security and dignity must be firmly rooted in a deliberately chosen attitude to human beings, namely conviction of *universal human equality of dignity and rights*.

The in-depth incorporation of this view and the drawing of conclusions from it in recurrent everyday tasks is an ethical-moral challenge to individual employees and to elderly care as an activity/organisation. Insight and understanding are put to the test when these principles come to be translated into action by caring services.

The "translation" from the nicely worded concepts to response in older people's homes and in situations where they need help has not always worked properly. This can have various causes, such as the implements needed for reducing distance. Another reason may of course be the one which has come in for most attention in the public dialogue, namely funding shortages. I have argued, however, and do so again now, that it is also necessary to scrutinise the use made of the available resources in the short and long term. This is one of several reasons why, in my report, I frequently return to the necessity of various preventive measures.

I have encountered a very strong interest in deepening the consideration of ethical and moral issues involved by elderly care and in training programmes leading to employment with the elderly. This pronounced interest in deepening the content of care I regard as a very great resource in a continuing process of development. It is my belief that resources of this kind must receive attention through measures showing the importance of their administration, and I have therefore stressed the value of training and research in a process of interaction with professional experience. Care of the elderly calls for long-term priority based on a fundamental consensus view.

Reflections from others

Many people have communicated their thoughts and suggestions concerning a deepening of the content of elderly care, based on a fundamental humanist consensus. This has been gratifying to me and beneficial to the inquiry. People have reflected on the present situation and the future and have described their concern over the emasculation of concepts like solidarity.

There is strong affirmation of the necessity of counteracting a collective response in caring services for the elderly, just as

elsewhere in the community. In very concrete terms, good individual response can mean an older person being enabled to retain his or her own morning routines even when living in collective accommodation.

In the final report I give examples of methods which serve to strengthen individual response. I wish to emphasise, however, in common with viewpoints communicated to me, that these methods do not exist in a vacuum. Like my suggestions for strengthening the position of individuals, they must be seen and must operate as expressions of individual employees and the activity having understood and being able to make inferences from basic views and guiding principles.

Of power and knowledge

My terms of reference mention that response can also be influenced by power relations and access to knowledge. Many people have remarked that realisation of the substance of the guiding principles begins with reflections on how one would like to be treated oneself. The great majority would surely object to being stripped naked and tended in front of strangers or referred to as "packages", but this has actually happened. Power questions in caring services ought, in my opinion, to receive greater attention. One step in this direction may be to make more detailed use, throughout the organisation, of the knowledge emanating from critical viewpoints, complaints and incidents. Meeting points need to be created for dialogues between older persons, next-of-kin, personnel and other representatives of caring services.

As stated in various connections that duties in caring services for the elderly are highly qualified and are becoming more and more demanding.

Rising demands in caring services for the elderly unconditionally call for an active accumulation and dissemination of knowledge. The content and levels of training must be brought more closely into line with the demands posed by reality.

I wish to make absolutely clear my conviction that, whatever the form of training on a particular occasion, its content must be characterised by a joint endeavour on the part of students and teachers/instructors to utilise the students' own previous experience, to analyse it and to relate it to new knowledge. An ethical perspective on the purpose and content of the activity must

have priority and must be applied to the interchange of knowledge. By the same token I stress the importance of improved communication between theory and practice, both in foundation training programmes and their relation to workplace training, and between research activity and "field work" in the care of older persons. I also focus attention on the need for ongoing guidance as a support for personal development and competence improvement through new skills, related to current needs in the duties of the working team.

Continuing development - some examples

Finally in this chapter I raise a number of questions which concern response in a wider perspective and, in my opinion, are going to acquire added importance.

We must draw conclusions from available knowledge concerning measures which *prevent* illness and allow for the great individual variations to which ageing processes are subject. That knowledge needs to be developed through research.

We must observe how new technology can change the conditions governing access to information, service and social contacts. Where older persons are concerned, there are both impediments and opportunities. User possibilities must be studied and developed, together with their social and psychological dimensions.

Through a clear allocation of roles we must find good forms of co-operation with the voluntary work done by various organisations.

Chapter 3:

Some perspectives on the situation of older persons, the conditions of ageing and the development of elderly care

This chapter sheds light on factors which, directly and indirectly, can influence response to older persons. Ass. Prof. Gerdt Sundström of the Institute for Gerontology, Jönköping, provided most of the supportive documentation. Among other things, this chapter deals with demographic developments, economic

conditions for older women and men, the housing situation, informal care and inter-municipal differences in caring services for the elderly.

One vital question concerns the balance between the resources committed to care in the individual person's own home and the resources devoted to special accommodation. It is observed that a growing proportion of resources goes on special forms of housing accommodation, while non-residential care is reaching progressively fewer.

Small rural municipalities devote a larger proportion of their resources to caring services for the elderly than other types of municipality. In Sweden as a whole, 17 per cent of the population aged 65 and over use some form of caring service.

As things now stand, the number and percentage of persons aged 80 and over are increasing. 17.4 per cent of the population in 1996 were aged 65 or over (1.5 million persons) and 5 per cent (421,000 persons) were over 80. The forecasts indicate that the number of over-65s will remain constant for the next few years. Persons aged 80 or over are expected to number about half a million in 2020.

The percentage of persons aged 65 and over and aged 80 and over is low in certain municipalities and regions and way above the average in others. Most people of very advanced age are women; at age 70, there are insignificantly more women than men, but at age 90 the women are 2.5 times more numerous than the men.

Economic circumstances, housing etc.

Seen as a group, older persons are financially better off today than used to be the case. But conditions prevailing in a group cannot be automatically transferred to its individual members. Pensions are the main source of income (85 per cent on average) for most older people. Quite a considerable number have certain other sources of income, at least early on in their retirement. These items of income tend to dwindle. There are, however, greater differences among pensioners than in any other group of the population. The oldest members, and especially the women among them, often have very small incomes and little in the way of capital assets, while the youngest, and the men especially, are quite wealthy. The statistics generally point to great differences in the pensions and other incomes of older men and women

respectively. Income and wealth statistics show that quite a large number of pensioners have savings, but these assets are unevenly distributed and can be "eaten up" by the rising cost of living.

The implications of user part-charges for persons dependent on elderly care are to be made the subject of a new Government Commission which will among other things investigate whether the level of these charges causes individual persons to refrain from using services.

As regards the housing situation among older people, one finds that one-tenth of pensioners at the beginning of the 1950s did not have homes of their own. That situation has clearly improved, and sub-standard housing nowadays is seldom a direct reason for older persons moving into special accommodation. Older people's housing standards can, however, be low in other respects, e.g. due to insufficient modification and poor access in the external environment. At the beginning of the 1950s, 27 per cent of older persons were living alone, while today the figure is over 40 per cent. It is mainly women who live alone. This rising proportion of single-person households, parallel to advancing age, is a Nordic pattern; internationally, single living diminishes in the upper age groups, due partly to a lack of support and assistance from the community.

It is also worth noting that about 70 per cent of women in Sweden and 30 per cent of men live alone during their declining years.

15 per cent of men and 21 per cent of women aged between 80 and 89 were living in special accommodation in 1996. Housing standards in special accommodation have risen during recent years, but deficiencies remain. 10 per cent of residents in 1996 were sharing a home with a person who is not their spouse.

This chapter also shows that various forms of private "senior housing" has emerged, often on a tenant-ownership basis. Non-public domiciliary services appear to be on the increase. Dependable figures are lacking, but it is believed that nearly one-tenth of persons between the ages of 75 and 80 make use of these services, ranging from "black cleaners" to the services of contracting and caring enterprises.

It was estimated in 1996 that about 5 per cent of financial resources in public elderly care went to private providers, in which case about 9 per cent of users were affected.

Family and immediate surroundings - care by next-of-kin

Legislation on the duty of adult children to take care of their parents if the latter could not provide for themselves remained in force until fairly recently in Sweden. Those stipulations were only abolished in 1979, and even then it was pointed out that the children's moral obligations remained. On the continent and in several other countries, the duty of maintenance still applies.

Contrary to all current suppositions, one finds that the family networks of older persons have grown stronger. Between 15 and 20 per cent of newly retired persons have a surviving parent or parents. More generally speaking, at a certain age nowadays we have a good many more surviving close relatives compared with the situation, say, in 1900. Amazingly many have one or more children at close quarters, the majority no more than a few Swedish miles away (one Swedish mile = 10 km). Communications and new technology have created growing opportunities for keeping in touch. A diminishing proportion of older persons are socially isolated: about 4 per cent of the entire population between the ages of 65 and 84, according to figures published by SCB (Statistics Sweden) in 1993. There are, however, differences in social contacts, and these are connected with economic factors, as is shown, for example, by a Stockholm survey in 1997. (S.-E. Wånell, the Stockholm Gerontology Research Centre).

Many older persons live on in or near the locality where they grew up. Swedish pensioners relocate less often, for example, than their French counterparts, even though certain of them move "back home" round about retiring age. Most relocations are within the municipal boundaries.

In-family assistance to the elderly is increasing, above all perhaps among those who have not yet become part of the domiciliary care (home help) system. When the need for care increases, a combination of in-family care and home help service often materialises. All the indications are that Swedes, as carers, are roughly as active as people in other Western countries. Several form of public support for next-of-kin have diminished, but there is growing use of "carer's allowance", a supportive arrangement for in-family care in connection with severe, often

life-threatening illnesses. In six out of every ten cases this means care of parents/in-laws, and in about 75 per cent of these situations the carer is a woman.

This chapter also deals with various principles for defining the onset of old age. Attention is drawn to the difficulty or impossibility of pinpointing a certain age at which people grow physiologically "old". It is noted that risks of dementia disorders are underestimated; certain studies suggest that at least 25 per cent are affected by such illnesses sooner or later. There are clear gender differences where illness and ageing are concerned. Men die earlier and often "abruptly", while women are afflicted by several illnesses of longer duration.

Utilisation of elderly care is discussed. These measures are tending more and more to target those in greatest need of care. Less extensive help ("service") is accounting for a steadily diminishing percentage of home help resources. There are, however, great local variations which cannot be easily put down to such factors as local government finance etc. G. Sundström (who contributed the input documentation for this chapter) believes tradition in different municipalities to have some part in the differences observed where elderly care is concerned.

Chapter 4:

Response in caring services and other public activity

The terms of reference required the investigation to shed light on the response to older persons in caring services and other public activity.

On the strength of very urgent needs, I have given priority to response in caring services, but in this chapter I also raise very important aspects of other public sector activity, such as accessibility in various senses, which can have a critical bearing on response.

I begin, with the aid of supportive documentation from Ass. Prof. Lars Andersson (the Stockholm Gerontology Research Centre), by focusing on attitudes to older persons and ageing. He notes among other things that attitudes have "always" varied. And there have always been strong connections with gender, social status, health status etc.

Not even "obsession with youth" is anything new, according to this study; it was very pronounced, for example, during the Renaissance. Purely generally speaking, though, younger persons do not appear to be particularly negative in their attitude towards older people. There is, however, according to the study a threat picture which consists in public debate having instilled such concepts as "wrinkly boom" to denote an increase in the percentage of the population who are of every advanced age. This can have laid the foundations of negative attitudes.

Among other things I declare that a vigorous, long-term prioritisation of elderly care can counteract tendencies of this kind. In this process it is essential to appeal for active participation by older people.

In this chapter I review various measures for older people and the way in which their form and content have developed, with special emphasis on questions of response. Municipal caring services for older people are urgently in need of restructuring. Daytime care, relief services, after-care and rehabilitation should be increased. The quality of assistance assessment and care planning must be reinforced.

A new objectives provision in the Social Services Act (effective from 1st January 1998) stresses that social services shall be mindful of the self-determination, privacy and security of older people. This requires measures to be designed individually and flexibly, both in domiciliary care and in special forms of accommodation. Distinct assessments of entitlement to assistance must guarantee the rule of law. Assessments and decisions must be followed up. Within the scope of a decision concerning assistance, the individual, in my opinion, should be given more say concerning the choice of measures, so that they will correspond to his or her habits, interests and general situation. The individual and his or her next-of-kin must also be well informed of where to turn with complaints and viewpoints about caring services.

The development of caring services for older people

Lengths of stay in hospital are steadily diminishing. This tendency means bigger demands for qualified inputs and care through municipal caring services for the elderly.

The support and help needed by individuals cannot be divided up into medical and social measures: needs are composite.

Deficiencies in medical care for the elderly have been widely referred to, especially where medical practitioners are concerned. Pensioners' organisations have noted this shortcoming with special reference to nursing homes.

Daytime activities, short-term care and rehabilitation are important, for example, as means of helping older persons to continue living independently. Charges for these services vary considerably. I see advantages in the possibility of including these charges in charges for domiciliary care: the inputs concerned are part and parcel of the support given to individual persons wishing to go on living in their accustomed surroundings.

Response in different environments and in "other public sector activity"

My remit requires me to investigate whether there are differences of response in different forms of special accommodation. An interview study has been carried out on my behalf by Ass. Prof. Owe Åhlund, Lund. That study was on too small a scale to be generalised, but it can give rise to important new research. No distinct differences of response could be demonstrated in different special forms of housing accommodation, but in certain of them there were older routines which could be reflected by the response received. Other surveys have shown that the domestic and immediate environment can underpin response and interaction. This has been shown by studies of group housing for persons with dementia and for persons with intellectual handicaps. Questions are asked concerning the future development of housing arrangements for older people and concerning the need to investigate the impact of collective forms of housing for older persons on individuals, next-of-kin and personnel.

Finally I turn to consider how response can be affected by accessibility in the physical environment, public and commercial services, information, cultural amenities etc. I note that these questions are highly important, not least in the context of a growth of continued independent living. Good access strengthens the ability of individuals to participate, to exercise self-determination and to preserve their mental and physical health. I have underlined that the question of accessibility also concerns next-of-kin and personnel supporting the individuals. In this chapter I note that additional and vigorous attention needs to be

paid to these questions, since a large proportion of older persons may have various functional impairments.

Chapter 5:

Personal support

This chapter shows that certain older persons may need some form of personal support in order to gain a hearing and exert influence in various connections. This applies, for example, to those who do not have any close relatives.

The legal position of individual persons is reviewed as a background to brief descriptions of various supportive arrangements. Otherwise I refer to the summary of Chapter 9, where the supportive arrangements are reiterated in proposals.

The function of *representative* is described, together with the possibility of obtaining support through a *guardian.* I observe the widespread supposition that a guardian is appointed for support in financial matters. But the law (the Code of Parenthood and Guardianship) also makes it possible for the guardian to provide support in other personal matters relating to the daily lives of individuals. Information measures are needed, however, in order to make this possibility known.

Personal support can also be given through a *contact person*, a theme which I elaborate through one of my proposals (Chapter 9). Other forms are also mentioned in this chapter, e.g. an experimental scheme of *personal representatives*, i.e. expert facilitators whose task is to co-ordinate various matters (housing questions, money matters, employment and activity etc.) together with the individual. Until now the experimental scheme in progress has mainly focused on persons with mental disturbances.

The individualisation which I describe in many connections could in my opinion be promoted through greater possibilities for individual persons to be given an *individual plan* of different inputs. In this chapter I describe how this possibility exists in certain other statutory instruments. There is a special advantage in the possibility of the individual (and, in certain cases, next-of-kin or a guardian) playing an active part in drawing up the plan and obtaining a comprehensive view of different measures, when they come into question and so on. The individual plan can also be a means of following up different inputs.

I also describe *personal assistance*, which is a form of personal support for certain persons with extensive functional impairment. Under the existing rules, reimbursement for the cost of this measure, assistance compensation, is not payable after the individual has attained the age of 65. The National Board of Health and Welfare has followed up the support given to persons (152 altogether) who formerly received assistance compensation and are now aged 65 or over. It found that nearly 60 per cent had received less or different assistance after this point. I refer to the summary of Chapter 9 and the proposals described there.

Chapter 6:

Response to next-of-kin etc.

In this chapter I note that next-of-kin or others close to the individual concerned are extensively active in providing older persons with support, care and attention. The volume of these inputs is hard to tell, but is generally taken to be a good deal greater than the volume of inputs from the community. Throughout the course of this inquiry, next-of-kin have communicated viewpoints on caring services, most often about shortcomings, but also suggestions for improvement. One important support, according to many is being able to *rely on the quality of inputs*, i.e. on their being performed in the manner agreed on. Next-of-kin have emphasised that what they want is tailor-made, individualised support, both practically and psychologically speaking. In this chapter I present a wants list from next-of-kin. Among other things, this includes access to good information, participation, respect for relatives' knowledge and experience, readily available counselling in various situations and good opportunities of relief, mainly through daytime activities for older persons but also in the form of short-term care. These activities need to be developed and made more variable.

Next-of-kin, like others, have observed that not all relatives are capable of taking part in caring activities. It is important to bear this in mind. Otherwise risk situations will arise in which excessive demands and isolation are experienced as coercion and at worst, can lead to abuses.

Some of the proposals I put forward (Chapter 9) concerning possibilities of strengthening the position of the individual also

concern next-of-kin, but it is essential to perceive the differing needs of those who provide support and those who receive it.

Chapter 7:
Of caring personnel

This chapter deals mainly with

- the manning of municipal caring services - numbers, composition etc.
- personnel training
- aspects of the work situation for personnel
- possibilities of augmenting individualisation by various methods and at the same time developing the duties of personnel.

In the light of comprehensive personnel statistics, I note that we have great changes ahead of us, among them the need for a great deal of new recruitment. Rising demand in caring services for the elderly call, in their turn, for massive training inputs. Both the content and levels of training will have to be analysed and altered. There is a similar need for changes in work organisation and leadership.

In my summary I dwell mainly on questions of personnel training which, throughout the course of this inquiry, has been emphasised as a crucial issue by various parties affected - next-of-kin, organisations, authorities and others. The main focus of attention has been on training programmes for social care, namely high school ("upper secondary school") with its health care programme, and post-secondary education (the social care programme). Students taking the high school health care programme are trained to work as nursing assistants and assistant nurses. The elderly and disabled care speciality of the post-secondary social care programme prepares students for service partly as assistance handling officers and supervisors.

Many employees received their basic training quite a long time ago, which means that we need to discuss, not only foundation training programmes but also subsequent training and opportunities of advanced training. One particular problem is that a quarter of nursing assistants lack the basic formal training for their duties. This is not to say that they lack knowledge and

experience, but the new demands of elderly care must also be met by means of new knowledge.

In this chapter I review the content of *the three-year health care programme in high school*. That programme includes at least 15 weeks' workplace training (APU). The Swedish Municipal Workers' Union has scrutinised this study programme and, briefly, finds

- that the programme is a good one but needs time to shake down,
- that the students are "employable" but that workplace introduction is also needed and is sometimes neglected,
- that more workplace training is needed,
- that co-operation between schools and working life needs to be improved,
- that the training of supervisors (i.e. those in charge of the students during their workplace training) must be reinforced,
- that employers must plan for a future rise in recruitment needs.

Post-secondary studies in social care have, since 1994/95, comprised 120 study points and lead to a University Diploma in social care. Examining the goals of this study programme and after describing its evolution, I note that many Government Commissions over the years have addressed the question of its mandatorship. Invariably they have concluded that this programme should converge with and/or be linked to post-secondary studies in social work (diploma courses etc.). Several commentators have observed that elderly care demands both social and medical inputs, and that this ought to be reflected by the structure of training programmes. It has been found that the training must be both broadened and deepened in order to match the demands made, for example, on supervisory staff in elderly care. Mention has also been made of the need for a research connection.

Summing up, I find that greater efforts need to be devoted to foundation training for nursing assistants and to training programmes for supervisory staff, assistance adjudication and other handling officers, training which, in keeping with several earlier proposals, I feel should tie in with education and research at schools of social work and public administration.

I draw attention to the responsibility of the employer for in-service training, and I see a need for current inventories at local level in order to facilitate strategic planning of training measures

for various groups. In particular I call, for example, for special efforts, something of a "spearhead competence", in areas concerned among other things with response to and communication with persons having various functional impairments. Some of these desiderata are presented in this chapter. In all training programmes, there must be strong emphasis on questions of response and ethics.

The working situation for personnel

Statistics concerning occupational illnesses and work accidents are passed in review. Nursing assistants etc. are the occupational group in the caring sector with most reported accidents and illnesses. These work accidents and occupational illnesses mostly concern musculoskeletal injuries in connection with lifting. Social and organisational factors (stress, deficiencies of work supervision and organisation) are other common causes.

The role of the National Board of Occupational Safety and Health as a supervisory authority in matters relating to work environment conditions is described. I show that, in its comments on the inquiry, the Board has pointed out important connections between work environment conditions and the possibility of achieving a good response to older persons.

Internal control of the working environment and the employer's duty, among other things, of verifying the employee's knowledge of the work, risks and working conditions generally, are also important with a view to avoiding poor response. Internal control must be conducted systematically and must also include work environment management plans.

Lastly in this chapter I deal with quality development and working procedures to strengthen an individual response to older persons. The importance of feedback on documented shortcomings to operations is emphasised as part of an active preventive strategy.

I review, among other things, qualities of assistance adjudication and the need for individual follow-up of the assistance given. Welcoming addresses, for example, are advocated (both in domiciliary care and in special accommodation) as a means of building confidence between staff, the individual and next-of-kin. Contact person activities (the appointment of someone among the personnel to take special responsibility of questions relating to a certain older person) are

described as a very important element, but I note that they require support and guidance.

Chapter 8:

Supervision, disciplinary questions, secrecy and fact monitoring etc.

This chapter is mainly a review of various enactments governing supervision, questions of liability and secrecy.

I present the differences I have noted concerning *supervision* of health and medical care and social services. In addition, I make reference to a report by the Parliamentary Standing Committee on social affairs, which states that supervision of elderly care will have to be improved and tightened up, e.g. in the matter of legal safeguards. I endorse this view, which I have described earlier in an interim report (SOU 1997:51). I attach particular importance to the Standing Committee's pronouncement concerning the need for a more distinct organisation of supervisory activities, which can play a decisive part in strengthening the position of the individual.

Relevant legislation is also passed in review concerning *the system of liability* applying to personnel in municipal health and medical services. I present viewpoints received concerning problems of demarcation which are liable to occur in municipal health and medical care. It is very often difficult to tell when non-authorised personnel are to be regarded as health care and nursing personnel and when they are not. There can also be deficiencies in routines of delegation between different personnel categories. Legislation on health care and medical services defines in detail the responsibilities incurred by health care and nursing personnel. No such regulations exist for social services. In view of the composite need of older persons for care and attention, with both medical and social inputs, I feel that the presentation of proposals on this subject is an important quality issue to the individual. (See also the summary of Chapter 9.)

Secrecy in the relation between next-of-kin and personnel has been discussed at the colloquies and round table discussions organised during the inquiry, and so in this section I consider the legislation. This is strict and does not permit a more "generous" view of the possibilities of divulging information to next-of-kin.

An exchange of information is possible by obtaining consent (in certain cases a silent, "presumptive" consent) from the individual, but it is my opinion that recurrent training and information are needed concerning the requirements posed by the legislation.

Other points dealt with in this chapter include the necessity of investigating certain response-related questions concerning persons with dementia and various questions of method in the care of dementia patients.

I go on to describe certain aspects of *advisory boards* and their important task of improving the possibilities of contact between patients and health care and medical personnel. These boards are required to give advise, support etc. to individual persons and next-of-kin and, where necessary, to be able to refer people to the right care provider and level of care. It has become apparent that the advisory boards need to become better known among the general public, but also among county council and municipal representatives of health care and medical services. In my view, the advisory boards could be developed into more of a "commissioner" for older persons and their next-of-kin. (See the summary of Chapter 9.)

This chapter also raises questions concerning the possibilities of investigating whether the vast amount of knowledge that has been gathered concerning complaints, viewpoints etc. about the content of care could be systematised in such a way as to augment the possibilities of monitoring the qualitative development of various activities. I also emphasise the importance of further development of national statistics concerning elderly care and various parts of its content.

Chapter 9:

Deliberations and proposals

Introduction

I have gathered my deliberations and proposals in Chapter 9. This chapter, however, belongs together with what has already been written in the report. The earlier descriptions contain examples of working approaches, inputs, training content etc. which have been developed in several quarters but which need to be disseminated and reinforced - in certain cases through the proposals made in Chapter 9, in others through inputs into short and long term

which I describe and advocate in connection with each particular field in the preceding chapters. I have also considered myself at liberty to go beyond my terms of reference in matters where I have found close connections with inputs and processes capable of developing the good response to older persons. This applies, for example, to important questions of personnel training.

Supervision of caring services for the elderly

I state that it must be established beyond any shadow of doubt that, in an equitable society, we safeguard older persons and their opportunities of a life in dignity. At the moment I find widespread and serious lack of confidence in the content of measures by the community. The connection between the national objectives, the overarching principles and reality is being called into question. Lack of confidence in future care is causing suffering to individuals and next-of-kin and creating anxiety among personnel. These things, taken together, can have the effect of impairing the content of care and causing bad response.

I am well aware that much good work is being skilfully and competently done by the existing supervisory functions. From the viewpoint of individual needs, however, I find that supervision is in need of reinforcement through better integration with various competencies, co-ordination of activities and clarity of task and functions. The new Social Services Commission is among other things tasked with examining the possibilities of developing more vigorous regional supervision under the same national mandatorship. This, I feel, should constitute a main alternative. The remit of the new Social Services Commission is to be concluded in March 1999, but it is my opinion that the Government should issue the Commission with supplementary terms of reference instructing it to present, at the earliest possible opportunity, an interim report on supervisory questions. In the reasons given for my proposal, I have indicated that I see a problem in this because it may be an advantage to have investigated other questions before taking a stand on supervisory questions. I find, however, that the situation in caring services for the elderly justifies swift action. An interim report from the new Social Services Commission could very well include a thorough analysis of existing supervisory functions and lead at all events to interimistic proposal for reinforcing the supervision of elderly care.

Wider responsibility for municipal health care and medical personnel

I recommend an expansion of the system of liability applying in municipal health care and medical services. By "system of liability" I refer to the regulatory system which exists concerning, for example, duties, disciplinary sections and supervision among health care and medical personnel. The rules indicating which persons are to be regarded as health care and medical personnel differ from one municipality and county council area to another. Municipal personnel can constitute health care and medical personnel to a lesser extent than their county council equivalents. Through my proposal I wish to reduce this difference.

In the reasons for my proposal I have referred to various reports by Commissions and other bodies, showing that municipal elderly care has been increasingly obligated to receive and care for persons with severe illnesses and functional impairment. In one report, the National Board of Health and Welfare has remarked that care of dementia patients has become a growing task for municipal caring services, together with terminal care. Judging by what is said in a report by the Commission on the Future Organisation and Funding of Health and Medical Care (HSU 2000 - SOU 1996:163), however, the care of dementia patients has not only become an increasing task for municipalities. According to the Commission, dementia care has to all intents and purposes become a municipal responsibility. The Parliamentary Standing Committee on Social Affairs addressed the growing care load on municipal health care and medical services in two reports during the 1996/97 session of the Riksdag. One conclusion which can be clearly drawn from a hearing conducted by the Standing Committee on Elderly Questions is that the special forms of housing accommodation have had to take over patients previously cared for, for example, in internal medicine and geriatric departments. Many of these persons require considerable inputs of medical care, technology and nursing. The Standing Committee goes on to state that the boundaries between municipal social services and, on the other hand, health care and medical services have in some respects become blurred in recent years.

These are the basic reasons for my proposal to expand the liability system in municipal health care and medical services. I have also pointed out that certain bodies included in my informal circulation for comment of the report on the shortcomings of care

(SOU 1997:51) have raised various problems connected with difficulty in deciding which persons, in municipal health care and medical services, have the status of health care and medical personnel and which do not.

My proposal is that all municipal personnel involved in health care and medical services in the form of care, examination or treatment of individuals have the status of health care and medical personnel. Under the Health and Medical Services Act, the municipalities are duty bound in this connection to offer health and medical care to persons in special housing accommodation. Each municipality is also required to offer health and medical care in connection with daytime activities. Furthermore, about half the municipalities in Sweden are responsible for home nursing. My proposal, then, is concerned with health and medical care in these activities.

In my opinion, it should be possible for the term "care" to be given quite a broad interpretation, on similar lines to those applying in county council health care and medical care. It should refer, not solely to direct care but to indirect care as well. This means, for example, that administrative staff can also be regarded as health care and medical personnel.

A wider system of liability, as I see it, is not only concerned with the system of liability in itself. It is also concerned with the professional role. The competence of municipal health care and medical personnel needs to be strengthened in response to the development which has occurred and can be expected to occur. Elevation of competence will be in the interests both of the municipality itself and of the employees' organisations. Furthermore, a higher level of competence may not only affect the performance of work but will also give it higher status.

Higher level of training for handling officers and supervisory staff

Shortcomings observed in the legal safeguards connected with assistance adjudication, as well as growing demands on the content of such procedures and necessary co-operation between several compentencies lead me to conclude that assistance handling officers/adjudicators must be more adequately prepared for their duties. It is my opinion, therefore, that the level of training for handling officers and supervisory staff in elderly care must be raised by means of connection with the schools of social

work and public administration in such a way that the training will lead to qualifications corresponding to the University Diploma in Social Work and will be more closely connected with research.

The "Knowledge Lift" for established employees

The so-called "Knowledge Lift" is a long-term scheme to give unemployed adults with incomplete post-compulsory schooling or none at all access to education which will give them this kind of competence. In addition, the scheme is also intended for employees with incomplete post-compulsory education or none at all.

According to information which I have received, roughly a quarter of the nursing assistants now employed in municipal caring services for the elderly have either incomplete post-compulsory qualifications or none at all. In order to meet what are already pronounced and growing demands in caring services for the elderly, I believe it is necessary for formal basic training needs to be taken into account. This training is a necessary point of departure for subsequent training and other forms of competence improvement. I propose that the Government should take steps to reserve a certain portion of the resources available in the "Knowledge Lift" for established employees in municipal caring services for the elderly.

Home nursing

It is in my opinion urgently necessary to accelerate co-operation and integration between areas of social and medical competence, e.g. in home nursing. A process of this kind is prompted, as I see it, by the composite need of individual persons for qualified and co-ordinated inputs involving several areas of competence. Documentation, in the form of comprehensive national statistics or descriptions of the development of the content and duties, is lacking with regard to the development of home nursing in municipalities and county councils. I propose that the Government should commission the National Board of Health and Welfare to carry out ongoing documentation at national level and to report on the development of home nursing in municipalities and county councils.

The advisory boards

It will be recalled that the Commission on the future organisation and funding of health and medical care (HSU 2000) has proposed a Patient Committee's Act (SOU 1997:154) which will supersede the existing Advisory Board Activities Act. The Commission proposes expanding the tasks of these boards so as to include certain social service tasks in municipal caring services. For my own part I feel that the field of responsibility should be expanded more than this. It is my belief that developments should move in the direction of authorising the advisory boards to deal with complaints regardless of whether they are prompted by shortcomings in a field of social or medical competence.

There has been widespread reference to shortcomings in the information supplied by disciplinary boards concerning their activities, purpose and working methods. I therefore propose that the Advisory Board Activities Act be made to include a provision making it the duty of the advisory boards to inform the general public of their activity and its purpose.

Contact person and guardian

The supportive arrangement of appointing a contact person can at present be granted as a service input under Section 10 of the Social Services Act. Little use is made of this arrangement where older persons are concerned, but I wish to develop the use of this supportive arrangement, and this should be done without delay. Support through a contact person can help to broaden the individual person's social network and can be a form of individual, everyday support. This arrangement can, in a simple manner, enhance the quality of the individual's everyday life and allow great freedom of choice according to the individual person's preferences. In order to bring about the development which I desire of this supportive arrangement, I feel that it should be codified as a right in the Social Services Act.

Just as the supportive arrangement of a contact person for the elderly should be developed, there should also be development of the supportive arrangement of a guardian.

The basic task of a guardian is to represent the person for whom he or she has been appointed. Guardianship includes safeguarding the rights of the individual, administering his property and taking personal care of him. The appointment can,

however, be limited to selection of these tasks. The guardian comes under the supervision of the Office of the Chief Guardian.

It is my belief that guardianship (with all three of the tasks described above) exercised by a dedicated person can effectively support the individual and strengthen his or her position in a number of important respects. A relative can be appointed guardian if he or she meets the qualifications. The guardian's task, as I see it, is not to replace personnel but, in the interests of the principal, to ensure that the quality of services corresponds to the preferences, interests and needs of the individual.

In my opinion, it should be possible for the supportive arrangement of guardianship to be developed within the scope of the existing rules of the Code of Parenthood and Guardianship. Information measures are needed in order to bring about development of this supportive arrangement on the lines which I advocate. The National Board of Health and Welfare should be made responsible for those information measures, which should primarily be addressed to individual clients, their next-of-kin and other persons close to them, and also to municipalities, interest organisations, next-of-kin associations etc. If the supportive arrangement of guardianship comes to be more widely used, I see no reason why its use should be confined to older persons.

Individual plan

There are several provisions and general recommendations, in health and medical services and elsewhere, concerning the making of individual plans. These plans, however, do not refer to social service inputs in connection with more continuous care of the individuals. In the course of my inquiries I have received viewpoints to the effect that provisions should be introduced on the making of individual plans in such cases, and I therefore feel that the Social Services Act should be made to include provisions enabling the individual to request an individual plan. Responsibility for the making of the plan should be vested in the social services, and the purpose of the plan should be to support work relating to the inputs which are needed. Through an individual plan, the individual person can be enabled to influence the measures which are planned and be given an overall picture of the timing of different measures. The plan should be constructed so as to provide an opportunity for follow-up and revision, and it should be continuously reviewed.

I see no need for confining the availability of an individual plan to any particular target group.

One important question connected with the planning of inputs is the co-operation which may come into question between different activities. With the individual person's consent, it should also be possible for the plan to be exchanged between different supportive activities.

Daytime activities, short-term care etc.

Individualised support with express objectives and considered individual planning of measures together with the stimulus and social participation which daytime activities and short-time care are capable of giving the individual, often makes it possible for the individual to go on living in his or her accustomed surroundings longer than there would otherwise have been the case. At present (December 1997), though not for much longer, these measures are regarded as measures of assistance. Their availability, expressed as a right to assistance, will cease on 1st January 1998 as a consequence of the restructuring of the system of assistance under the Social Services Act. Alarming reports of qualitative deficiencies in the support given to persons living on in their accustomed surroundings leave me, nevertheless, to put forward this proposal, despite the regulatory change recently enacted by the Riksdag. If there is no entitlement to these inputs, the result may be progressively greater numbers moving into special forms of housing accommodation, even if they do not wish to relocate. I do not feel that special charges should be made for daytime activities and short-term care.

Support through personal assistance

Following its 1997 evaluation of the disabled reform, the National Board of Health and Welfare takes the view that the question should be investigated of whether persons with a personal assistant and national assistance compensation should be enabled to retain this support after age 65. I have noted that in certain municipalities the individual is allowed, after age 65, to retain the assistance in the same form and to the same extent, in spite of the national assistance compensation being discontinued. Compensation of this kind cannot be paid off after the

beneficiary's 65th birthday. In other municipalities, the support deteriorates. I propose that a person receiving personal assistance under the Support and Services (Certain Functionally Impaired Categories) Act (LSS) at the time of his or her 65th birthday should be allowed to retain his entitlement to a personal assistant and national assistance compensation thereafter. I propose that this right should continue for as long as the person concerned is regularly housed and entitled to an input.

A common structure for knowledge monitoring

Within the health and medical care sector, there are several bodies to which people can turn with viewpoints and complaints concerning caring services. Deficiencies of response, quality and content are documented, for example, by health and medical care advisory boards, in the Risk Database (RDB) at the National Board of Health and Welfare, by the Health Services Disciplinary Board (HSAN) and by Patient Insurance. My exploration has shown that social services do not have the same systematic documentation of reports, viewpoints and complaints from individual clients and their next-of-kin. National systematisation of information concerning complaints to supervisory bodies by individual clients and next-of-kin in the health and medical sector are also important. I have observed that viewpoints and complaints lodged by older persons and others close to them are an invaluable source of knowledge. This knowledge needs to be made better use of in quality management and preventive activities. In particular I would call attention to the importance of devising, in the context of domiciliary care, procedures for a systematic processing complaints and viewpoints. It is in my opinion desirable for information in the databases to be systematised in a similar manner. I believe it is particularly important to be able to follow the development of quality and content of care for the very oldest persons, i.e. those aged 80 and over, who are in greatest need of care and attention, and I therefore propose that the Government instruct the National Board of Health and Welfare to investigate the feasibility of a joint project with a view to the co-ordinated systematisation of reports, viewpoints and complaints from individual clients and their next-of-kin, as well as "Lex Maria reports". A project of this kind, if feasible, should be entrusted to the National Board of Health and Welfare.

Need for a research strategy

In relation to research needs and to the extent of the research field, research concerning older persons, ageing and elderly care receives little attention and is allotted relatively small amounts of funding by various research financiers. The Government should therefore, in my opinion, initiate a concerted, long-term strategy for research concerning older persons, ageing and elderly care. Areas which, in my opinion, need to be analysed and made a subject of policy measures include:

- co-operation between training/education and research,
- the reciprocal flow between research and "the field", and the dissemination of research findings beyond the research community,
- the relationship between specific gerontological research and research in other fields with a bearing on older people and their social conditions,
- ways of supporting interdisciplinary research projects which have difficulty in acquiring a "right of abode" in any particular discipline.

Use of quasi-coercive methods

Several of the complaints passed on to me, above all from next-of-kin, concerned the use of what, in caring services, is sometimes referred to as "gentle" coercion. This means various kinds of restraint to prevent someone, for example, from falling out of a wheelchair or off a toilet seat. These arrangements can take the form of tying down with sheets etc. Relatives, even though they can to some extent understand the intention of preventing someone from falling, have found this to be a degrading and inadequate response. In this connection relatives have among other things questioned manning levels, work organisation and work supervision. In certain situations the personnel have been able to reply that they are entitled to take the measures referred to when prescribed by a physician. In other cases the personnel have only indicated that "that's how it's always done". Occurrences of these kinds have above all been reported from special forms of housing accommodation.

I propose that the Government should instruct the National Board of Health and Welfare to investigate the use of methods of

a coercive nature in the care of elderly persons, above all in the care of persons with dementia and dementia-like conditions. At the conclusion of the remit, the Government should decide on the need for legislation in this matter.

Chapter 10:
Consequences of my proposals

In keeping with my remit, I put forward proposals which can help to remedy deficiencies and abuses in response to older persons and which in the long term can promote the development of a good response. I have found that the areas in which I have chosen to make proposals have an essential bearing on the development of the quality and content of caring services for the elderly, in both the short and the long term. Conditions for the elderly and the development of elderly care are in every respect welfare issues. Measures are needed by the State, the County Council and the Municipalities in order to safeguard the self-determination of older persons and to give them security and dignity in the caring context. I found a need to strengthen the position of individual clients and their next-of-kin in the caring sector. Preventive measures in the broad sense must, in my opinion, be considerably developed. It is also my opinion that there must be stronger and distinct supervision in order to assert the right of the individual client to self-determination, privacy, security and dignity.

The stipulations concerning assessment of public financial commitments (Dir. 1994:23), which applied to all Government Committees/Commissions, mean that every such body must show how proposals which entail a growth of expenditure or a reduction of income can be financed within the frame of reduced or unchanged total resources. I have found cause to depart from these instructions as regards the proposal concerning personal assistant and assistance compensation. I justify this by referring to the unequal treatment existing today. Clients in certain municipalities are allowed to retain this support in the same form and to the same extent when national assistance compensation is no longer paid, while in other municipalities the support is reduced. Persons with severe functional impairment should be treated equally throughout the country, and so there is cause for accepting this expenditure. It is, of course - and has been ever since the support was introduced - very difficult to justify a

deterioration on account of a certain age having been attained - an age, moreover, at which the need for support if anything increases. As regards the rest of my proposals, it is possible that, in total figures, they may lead to certain increases of expenditure, but these are very difficult to estimate. However, in view of the vital deficiencies which emerged from the mapping and which - despite many good efforts in caring services for the elderly - have dramatically transformed public confidence in caring services for the elderly, I feel that any additional expenditure of this kind is defensible. This is a matter of credibility, affecting conditions far beyond the scope of caring services for the elderly.

FRITZES
Postadress: 106 47 Stockholm
Fax: 08-690 91 91, Telefon: 08-690 91 90

ISBN 91-38-20807-5
ISSN 0375-250X