

Summary

Chapter 1

This report highlights the challenges associated with prioritising between older and younger users of care services. The report gives an overview of how services to younger (under 67 years) and older users (especially those over 80 years) have developed in the past 20 years and discusses possible explanations of the growth in services for younger users. In particular, effects of increased judicialisation of user rights are in focus. The report also investigates whether the growth in care for the younger group has affected services for the elderly, and which challenges municipalities will face when prioritising. Finally, we compare our findings with research done in Denmark and Sweden.

Chapter 2

This report uses four data sources: 1) register data, 2) laws and regulations of user rights for elderly and younger users over the past 20 years, 3) a case study of five municipalities and interviews with key informants in the health and social services sector, 4) research in Sweden and Denmark and talks with distinguished researchers in the two countries.

Chapter 3

Data from the Norwegian municipality-state-reporting (KOSTRA) are used to describe the development of nursing and care services for younger and older users in the past 20 years. The data show that:

- There has been a substantial growth over the past 20 years.
- The workforce (as measured by FTEs) for the care sector has increased from 75,613 in 1992 to 126,227 in 2010. This implies an increase by 50,614 FTEs.
- Most of the new workforce has benefitted younger users.
- Institutionalised services for the elderly have been reduced. The number of recipients of home care among people in their 80s or older has fallen from 400 among 1000 in 1992 to 342 in 2011.
- In 1992 seven out of 1000 inhabitants under 67 years received home services, in 2011 they were 16 out of 1000 inhabitants.

Chapter 4

Several reforms and action plans have been initiated in the last 20 years, but none of these has been formulated as a law on individual rights. The review of the legislative history of the new Law for health and care services also shows that no age group or diagnostic group has received greater rights over other groups. The same applies to the Law of patient and user rights. The law and documents from the legislative history use general descriptions, with equal rights for all groups, regardless of age.

Nevertheless, a brief review of some ongoing debates in the care field indicates differences in treatments of older and younger users. These differences cannot be justified by the law, as already pointed out by governmental audits. Differences in treatments have

evolved through practice and by how municipalities have interpreted terms such as “needs” and “coping”.

The review shows a progressively greater emphasis on “normalisation” in the sense of a common law and common structures for all users, yet with adaptation and specific plans for individuals as well as user involvement. The principle of normalisation implies that what may have been formalised differences in treatments between groups is now abolished in the law. Nevertheless, the emphasis on individual adaptation and individual needs legitimises different treatments, as long as the differences in treatments are justified by individual needs. Variations in needs and life circumstances will thus have a strong effect on the services an individual receives. Different emphases on needs and different abilities to make use of the options that are given by the common law may result in discrimination between groups -- between old and young, and among groups at the same age.

Chapter 5

The informants in the case study suggest several explanations for the growth in care for the younger users. These explanations fall into three main explanations:

- *The ideology of what is good care has changed.* The main reason for this is said to be major reforms and escalation plans, which give the municipalities responsibility for services to an increasing number of younger users outside institutions.
- *Pressure from some groups of younger users and their supporters to gain user rights.* Increased awareness of user rights, and changes in people’s expectations of what the municipalities can do and what they can take responsibility for is also said to have affected the growth in care services. The fragile elderly, drug users, and people with mental illness are said to be less likely to use and fight for their rights. Younger disabled people are said to be the group most conscious of their rights.
- The third main explanation is said to be *changes in the hospital sector.* For several years an aim has been to reduce stay in hospitals. Simultaneously, the development of medical technology has extended offers that municipalities are able to provide.

Several informants stated that the growth in the care for the younger has weakened the services for the elderly. They suggest that not enough resources have been provided for the new users and that the municipalities distribute services within tight economic constraints. Several informants indicate that some groups of younger users are prioritised somewhat higher than older users. Major reasons for elderly receiving less services is said to be that the elderly are more frugal and that relatives do not fight as hard for the elderly users’ rights as relatives fight for the younger users’ rights. Even workers in the services, local politicians, and in some cases employees of County Governors are said to more easily sympathise with the desires and needs of the younger than the older users.

Chapter 6

There are several similarities between the development of the care sector in Norway on the one hand and in Sweden and Denmark on the other hand. Similar to Norway, reforms in the two other countries have resulted in the municipalities being responsible for a growing number of young users. User rights have increasingly been judicialised, both in Denmark and Sweden. In contrast to Norway, both countries have implemented special laws for services, such as having personal assistants only for users below 65 years. Research in Sweden shows that users receive significantly more hours of help from personal assistants than from home services, this is true both for older and younger users. Some younger users receive help both from a personal assistant and from home services. Researchers in Sweden, Norway, and Denmark point out that the ambitions to strengthen users' rights and to improve services for disabled people have been significantly stronger than the ambitions on behalf of other groups, such as the elderly, drug users and people with mental disorders.

Sweden and Denmark have introduced user choice to a much greater extent than Norway. Research in both these countries suggests that user choice produces winners and losers. The introduction of user choice seems to benefit the elderly much less than the younger disabled people. Only few of the sickest and frailest elderly with extensive need for care, who often also have dementia or other cognitive impairment, use the opportunity to choose. Younger people with psychological or cognitive impairment also seem to make little use of the opportunity to choose the service provider or to influence the content of the service.

Chapter 7

The final chapter discusses why the driving forces behind the growth in care for younger have not also acted as driving forces for care for the elderly. The following explanations are discussed:

- Care for the elderly is seen as being completed, with no need for expansion.
- A refund scheme is established for specially demanding younger users. Very high costs for individual users under 67 years are left largely to the state. This might contribute to older people with substantial support needs being less likely than younger people with a similar level of functioning to receive support to stay at home.
- The understanding of “needs” varies dependent on the life stage of the user. The support services may assume that younger users have a need for social contact, training/stimulation and personal hygiene at a higher level than similar “needs” among the elderly.
- Younger users are more rights-conscious, while older users are perceived as modest, humble, and grateful to receive anything at all.
- The emphasis on rehabilitation and employment may explain why younger users receive more nursing and care services than older users.

- Different professional traditions. Services aimed at elderly have traditionally put less emphasis on socialising, exercise and coping in daily life.

Based on the study, we have identified a set of key challenges for the municipalities:

The municipalities face great challenges, both economically and when seeking new staff. These include an increasing number of elderly, an increasing number of people with chronic diseases, and improved health treatments resulting in more people surviving but being dependent on help from health and care services for many years to come. Increased life expectancy also leads to increasingly more complicated and complex diagnoses, requiring greater expertise to handle. The Coordination Reform, implemented in 2012, is perceived to reinforce the development towards municipalities receiving an increasing number of heavy users who require significant personnel resources, and who must be helped by health care professionals with high medical expertise. We also witness a continued growth in the number of young users of care services.

An underestimated challenge ahead seems to be an increase in the number of younger users with psychological disorders and drug users. This is a challenge for existing resources, yet also a challenge because municipalities find it difficult to provide services that meet the needs of these users. A key question that may need consideration is whether the municipalities have the resources to provide services to the heaviest users in services for substance abuse and psychiatry, and whether the specialized services should be given greater responsibility for providing services to them. Another important question is how the care of the elderly will be affected if there is a greater gap between resources and the tasks to be carried out by municipalities. Research in Sweden indicates that the services for the elderly have suffered after economic recession has made cuts in care services necessary. This development is said to have led to increased gender and class differences, because women in families with little education and low income to a greater extent have had to care for their parents, while affluent elderly obtain private services in a growing commercial market.

Finally: We have seen, in particular through the case study, that the understanding of “needs” varies with the user’s life stage. A fundamental way of thinking is that users should be enabled to live a life that is most similar to the life of other people in the same life stage. Thus, it is important to discuss what should be considered as “a normal life” for people at 15, 45, 75, or 90 years. It is reasonable to question that “normal” for older users would be a relatively passive life, largely dependent on help from others. There may be a need for a broader debate about what people of different ages, with different needs for services, can expect of public action, and what should be the aim of these services.