# Policy Instruments in the Organization of Long-term Care and Social Support

What can the Dutch Government learn from the Use of Policy Instruments in the Organization of Long-term Care and Social Support in Sweden, Denmark, Germany and England for the Development and Implementation of the Dutch Social Support Act?

# Final thesis

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The Hague, October 2004

Z afus Erasmus Universiteit Rotterdam Ministerie van Volksgezondheid, Welzijn en Sport



# **Executive Summary**

In this thesis we present an international comparative analysis of differences in the application of the mix of policy instruments in the organization and steering of long-term care and social support for the elderly, the disabled and people with psychiatric problems on a decentralized or local and regional level in order to guarantee a certain level of quality, accessibility and affordability of long-term care and social support. In particular the dividing line between care, social support and no support at all in the different countries will be starting point of the analysis. At the same time the mix of policy instruments used to improve the policy goals quality, accessibility and affordability of long-term care and social support in each country is compared. This study compares five countries, the Netherlands, Denmark, Sweden, Germany and England, based on a framework in which policy instruments are categorised according to the mentioned policy goals. The four foreign countries have been selected because they all differ in the institutional structure of their health care system and welfare state model.

# **Uitgebreide Samenvatting**

Met de voorgenomen introductie van de wet Maatschappelijke Ondersteuning (WMO) in 2006 treedt er een grote verandering op in de organisatie van de langdurige zorg in Nederland. Onder de WMO krijgt de gemeente een grote rol in het vormgeven van beleid en uitvoering van voorlopig huishoudelijke zorg en begeleiding voor mensen die langdurig ondersteuning nodig hebben. De scheidslijn tussen zorg en welzijn/ondersteuning is bepalend voor datgene waar burgers straks wel of niet recht op hebben. De WMO kent niet het recht op zorg zoals nu geformuleerd in de Algemene Wet Bijzondere Ziektekosten (AWBZ), dit betekent een verlies van zekerheden voor burgers. De vraag die opkomt, is dan ook hoe we in Nederland basiswaarden van zorg zoals kwaliteit, toegankelijkheid en betaalbaarheid behouden en welke beleidsinstrumenten de lokale en centrale overheid daartoe ter beschikking staan. Aangezien een aantal West-Europese landen al langer ervaring heeft met een overheveling van langdurige zorg naar de lokale overheid willen we kijken naar de wijze waarop zij de langdurige zorg en ondersteuning georganiseerd hebben en hoe zij de basiswaarden garanderen.

In deze scriptie is een verkennende internationale vergelijking uitgewerkt van de verschillen in het gebruik van beleidsinstrumenten in de aansturing en inrichting van de langdurige zorg en ondersteuning voor ouderen, gehandicapten en personen met psychische problemen op het decentrale gemeentelijke of regionale niveau in Nederland, Denemarken, Zweden, Duitsland en Engeland. De buitenlanden zijn zodanig gekozen dat zij allen uit een andere institutionele structuur van gezondheidszorgsysteem en welvaartsmodel voortkomen. Het onderzoek vergelijkt op basis van een raamwerk waarin de beleidsinstrumenten gebaseerd op de theorie van Hood<sup>2</sup> en een aantal van de basiswaarden afgeleidde beleidsonderwerpen<sup>3</sup> met elkaar in verband zijn gebracht. Belangrijk uitgangspunt in de analyse is de context van het zorgsysteem in het desbetreffende land en meer specifiek de scheidslijn tussen zorg, welzijn en de gebieden waarop in sommige landen niets geregeld is.

Het onderzoek maakt duidelijk dat de ontwikkeling van de WMO in Nederland geen vreemde ontwikkeling is, gezien de organisatie van de langdurige zorg in de vier andere vergeleken Europese landen. Een conclusie van het onderzoek is dat een volledig terug trekken van de centrale overheid op het beleidsterrein van de langdurige zorg en ondersteuning niet gewenst lijkt te zijn. Dit omdat ontwikkelingen op het terrein van innovatie, professionele standaarden, cliënten participatie en kwaliteit daarmee mogelijk stil vallen. Met gebruik maken van kaderwetgeving en subsidies kan de centrale overheid innovatie op deze terreinen ondersteunen en stimuleren. In het geval van cliëntenparticipatie kan er ook gedacht worden aan een lokaal door burgers en (potentiële) cliënten inspraakorgaan over ondersteuningsfaciliteiten. Ook voor de ontwikkeling van toezicht op de

<sup>&</sup>lt;sup>2</sup> Hood maakt onderscheid tussen: nodality based, treasury based, authority based en organization based instruments waarmee hij achtereenvolgens in grote lijnen communicatieve, financiële, wetgeving gerelateerde en overheidsuitvoering onderscheid.

<sup>&</sup>lt;sup>3</sup> Te weten: kwaliteitsstandaarden, quality assessment, inspectie, professionalisering beroepsgroepen, innovatie, transparantie, klachtenregelingen, cliëntparticipatie, keuzeondersteunende informatie, kostenbeheersing, indicatiestelling, eigen bijdragen en ondersteuning van informele zorg.

ondersteuning is een rol weggelegd bij de centrale overheid, mede ook om te voorkomen dat de centrale overheid in een reactieve positie wordt gedrongen naar aanleiding van incidenten. Het is aan de lokale overheid om het toezicht vorm te geven op het terrein van de ondersteuning. Het advies is om verder onderzoek te doen naar hoe in de onderzochte landen toezicht en inspectie exact is vorm gegeven. Ook op het terrein van de invulling van de zorgarrangementen, voornamelijk de invulling van de full-package (een indicatie voor de zeven huidige AWBZ functies die in de WMO gehandhaafd blijft) brengt het risico op ongelijkheid met zich mee en daarom blijft bemoeienis van de centrale overheid geboden. Omdat er op dit moment een wettelijk klachtrecht is voor de langdurige zorg lijkt het zeer onjuist om in de ondersteuning hier niets voor te regelen. Voor de lokale overheid is het dan ook van belang om een lokale klachten procedure te organiseren mede om een vloedgolf aan rechtszaken te voorkomen. De centrale overheid kan dit bijvoorbeeld afdwingen door een prestatieveld rondom klachten expliciet op te nemen in de WMO. Een ander terrein waar de lokale overheid en de centrale overheid afspraken moeten maken over de taakverdeling is de ondersteuning van de informele zorg. Op dit moment is ondersteuning een vooral financiële aangelegenheid van de centrale overheid. De ondersteuning van informele zorg kan in de toekomst onder zowel de AWBZ als de WMO plaats vinden. Dit maakt dat het onwenselijk dat informele zorgverleners met verschillende soorten financiële regelingen te maken krijgen. Dit zou er voor pleiten financiële regelingen voor ondersteuning op het centrale niveau vorm te geven. Het is aan de lokale overheid om informatie te genereren met behulp van monitors, ten bate van transparantie en keuze ondersteunende informatie. De transparantie op het terrein van prijs - kwaliteit verhoudingen is ten bate van de gemeente om op basis hiervan goede afspraken te kunnen maken met private aanbieders. Het is dan ook logisch dat de lokale overheid de eisen stelt aan de aanbieders aangaande de informatie die zij wil ontvangen ter verkrijging van transparantie. Het is aan de lokale overheid om de indicatiestelling rondom de maatschappelijke ondersteuning vorm te geven en de toegangscriteria te bepalen, dit alles om de kostenontwikkeling in de hand te houden. De Nederlandse gemeenten zijn beperkt in de mogelijkheden om kosten te beheersen, ze kunnen nauwelijks extra lokale belastingen heffen voor aanvullende inkomsten. Dit maakt dat de regie over het pakket, de toegangscriteria en de eigen bijdrage op het lokale niveau belangrijker worden. Advies aan de gemeente is om de mate van aanwezigheid van informele zorg mede bepalend te laten zijn voor de indicatiestelling, zoals nu ook in de AWBZ gebeurt.

Een belangrijke beperking van het onderzoek is gelegen in de ongelijkmatige scheidslijnen tussen gezondheidszorg, langdurige zorg en ondersteuning/welzijn. Dit maakt mede dat de conclusies met enige voorzichtigheid gehanteerd moeten worden. Ook een ongelijkmatige beschikbaarheid van informatie, veel over ouderenzorg en weinig over gehandicaptenzorg en chronische psychiatrie, draagt hieraan bij dat conclusies met enige voorzichtigheid zijn gesteld. Op basis van dit onderzoek is duidelijk dat werkbare modellen in andere landen niet zonder meer over te nemen zijn in de Nederlandse situatie. Zo zijn er duidelijk verschillen in de voorzieningen die de vijf Europese landen aanbieden onder de noemer zorg en welzijn / ondersteuning. Ook maakt het onderzoek duidelijk dat er geen ideale situatie is; ieder systeem kent zijn tekortkomingen. Ook verschillen de systemen qua context en historie teveel. Keuzes moeten daarom altijd worden vertaald naar de Nederlandse situatie.

# **Preface**

After a little bit more than two years of combining studies and work, we have finally arrived at the phase of graduating. This study is the final part of our Master's program at the Faculty of Social Sciences, Section Public Administration of the Erasmus University of Rotterdam.

Before we wish the reader of this report joyful reading, we would like to thank the people who made it possible for us to carry out this research project. At first we would like to thank mr. R. Bekker, Secretary General of the Ministry of Health, Welfare and Sports (VWS), who has offered us the possibility to carry out our research project within the Ministry of Health, Welfare and Sports. Then we are very grateful for the time and effort professor C. Pollitt, our supervisor from the Faculty of Public Administration, invested in this research project. We appreciate his critique which helped us to stay on our initial track. We also want to thank our second reader dr. S. van Thiel.

Furthermore we are grateful for the help we got from mr. Kasdorp working at the Council for Public Health and Healthcare (RVZ) and drs. A. Goris of the National Institute for Care and Welfare (NIZW). They have made it possible that our research questions could be integrated in a large international research project on the organization of long-term care and social support. We also would like to thank mrs. P. Kolni of the Swedish Trade in The Hague and mrs. C. Pedersen of the Danish Ministry of Health in Copenhagen, Denmark for their information. Without the help of these persons we would never have been able to finish this report in the time span we did and as detailed as it is.

Subsequently we would like to say thanks to all our colleagues at the Ministry who came up with instructive remarks on our research project, invited us to participate in conferences to expand our international network and sometimes had to deal with our 'busyness' in writing this report. Last, we would like to thank our families and friends for their support. They never lost interest in the progress of our study and when we lost the interest and motivation they always came up with new ideas to go on or ways to relax. Especially we would like to thank drs. M. Kroese for checking the spelling and grammar of this report. We hope that reading this report will bring you as much joy as the research itself has brought us.

The Hague, October 2004

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# 1. Introduction

# 1.1 Introduction

In this chapter the origin of the study, the objectives and central research question will be described. The central research question can be subdivided into some more specific questions, which will be specified in section three. These smaller research steps will lead to an action plan and research method. In the fourth section it will be explained which steps will be taken, how these will be taken (what kind of research method) and why they are taken. All these will be subject of the fourth section. The fifth and last section contains the structure of this thesis will be drawn.

# 1.2 The Origin of the Study

Historically care for the elderly, the mentally and physically disabled and the psychiatric patients was in the hands of nuns and the convent or civil society. After World War II the Dutch government realised they had a task in taking care of vulnerable groups in Dutch society. With the introduction of the General Exceptional Medical Expenses Act (AWBZ), the first step was made in formulating long-term care <sup>4</sup> for exceptional medical expenses people could normally not pay for themselves. Currently, the Dutch long-term care system financed by the AWBZ is facing rising demand and costs. An ageing population has major consequences for the amount of care that the Dutch inhabitants collectively provide as a society. During the development of the system more and more care-products, which were in earlier days part of normal living and individual expenses became delivered on the AWBZ. Unless the long-term care system is being modernized, the contributions people will have to pay for the AWBZ will rise from just over 13% of taxable income now to between 20 and 25% within the next 15 years. Moreover, one out of every three school-leavers would have to go to work in the care sector in 2020 simply for us to have sufficient personnel.

The Dutch government is preparing a great change with the introduction of a new law called the Social Support Act. The intention is to introduce the new Act in 2006. So far, the municipalities had a small role concerning long-term care and social support. The fact that local government in the future has to make their own policy on long-term care and social support is a big effort. Implementing this new act on the local level means a change in tendency within Dutch long-term care. For example, in the Netherlands there is no experience with the implementation of house help or personal care on a local level, or with the surveillance of the delivered support. The requirements municipalities must meet will be formulated in the Social Support Act in general terms. It will be up to the local authorities to decide exactly how they implement the Act. The municipalities have to find out in which manner and with which instruments they can implement the Social Support Act.

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<sup>&</sup>lt;sup>4</sup> Long-term care is defined by the Washington Institute of Health as 'a variety of ongoing health and social services provided for individuals who need assistance on a continuing basis because of physical or mental disability. Services can be provided in an institution, the home or community, and include informal services provided by family or friends as well as formal services provided by professionals or agencies' (Ter Have, 2004).

At the same time the central government no longer interferes with the quality of care or the accessibility. Central legislation concerning patient rights or participation is no longer of application.

The Social Support Act will provide services to support people with limitations, and promote their independence and their participation in mainstream society. It aims at keeping the General Exceptional Medical Expenses Act affordable in an ageing society by abolishing the right for care or help and transferring the responsibility for the deliverance of affordable services to the task field of the local authorities. The local authorities, In the Netherlands the municipalities, will provide services tailored to fit individual needs and adapted to local circumstances. The AWBZ will revert to what it originally was: a law giving people access to truly unaffordable services. This will assure solidarity between the healthy and the sick and between different generations. The Social Support Act aims local developments at municipalities in supporting its own citizens to participate in society. It also aims at closing the chain of care in developing one-counter for all citizens' questions. Only the municipality (as a local governing board) can make it possible that the desired, but nowadays stagnating, social participation of people with a disability or the elderly, gets a new impulse. The Social Support Act also aims at making a valuable contribution to strengthening of local democratic processes. In the meanwhile there are also topics which may be important and which are not formulated at all.

International experience with the implementation and organization of long-term care and social support on the local or regional level can be of help when deciding which instruments in the organization of long-term care can be used when implementing the Social Support Act and organizing the delivery of long-term care and support in the Netherlands.

# 1.3 Research Questions and Objective

With a view to developments described above, we have chosen the following objective for our study:

#### Objective

To make recommendations, based on the experience of the organization of long-term care and social support by central, regional and local governments in Denmark, Sweden, Germany and England, for ways in which the new Social Support Act can be developed and implemented in the Netherlands.

'Ways' can be defined in different senses. The first would be the way in which the local government organizes and implements the Social Support Act. In this case 'way' can be defined as 'with which instruments can the local government organize the long-term care and support'. On the other hand 'ways' can be defined as the topics in the implementation of the Social Support Act from which the central governments can reasonably withdraw or, rather, should still carry on its steering and/or control tasks. This leads to the following twofold central question for this study:

#### **Central Question**

In the context of the new Dutch Social Support Act, what lessons can central and local authorities in the Netherlands learn from the mixtures of policy instruments used in Denmark, Sweden, Germany and England to guarantee a certain level of affordability, quality and accessibility of long term care and social support?

The research limits itself to the see whether in the different countries certain instruments are used on specific topics to obtain and improve quality, accessibility and affordability of long-term care and social support and to see what the Netherlands can learn from this. It is therefore mainly a prescriptive research.

To answer the above prescriptive research question, the question can be subdivided into some more specific questions:

#### **Derived Research Questions**

- 1. What does the practical application of values affordability (cost control), quality and accessibility offer to the study of long-term care and social support policies (comparative model determination-question)?<sup>5</sup>
- 2. What does theoretical literature on policy instruments offer to the study of long-term care and social support policies (comparative model determination-question)?<sup>2</sup>
- 3. Which general features have long-term care and social support policies in the Netherlands, Denmark, Sweden, Germany and England (context-question)?
- 4. Which policy instruments (based on derived research question two) are used on the topics of investigation determined in the first derived research question in the organization of long-term care and support in the Netherlands, Denmark, Sweden, Germany and England (comparison-question)?
- 5. What can Dutch central government learn for the development of the Social Support Act from the comparison made in derived research questions three and four taking into account the distinction between care and social support as could be determined from the third derived research question (conclusions)?
- 6. What can Dutch local governments learn for the implementation of the Social Support Act as initially proposed from the comparison made in derived research questions three and four taking into account the distinction between care and social support as could be determined from the third derived research question (conclusions)?

Looking at the above research question you can conclude that the proposed study mainly is socially relevant in the perspective of the development of the Social Support Act (Geurts, 1999). But the study

<sup>&</sup>lt;sup>5</sup> Although in theory it is not necessary to mention derived research question 1 and 2 separately, since they can be seen as part of the umbrella question 'derived research question four', these two questions are mentioned specifically to give insight to our line of reasoning. With mentioning research question 1 and 2 separately we made a difference between the theoretical and the empirical side of the comparison.

also can bring some scientific new understandings, explanations and clarifications or new illustrations in relation to existing or new theories, methods or facts<sup>6</sup>. In our study especially the relevance in the field of methodology and in description can be important. We hope to find and be able to describe the long-term care and social support system more clearly and comprehensive as someone else did before. This may hopefully lead to a new body of knowledge for the development of the Social Support Act. In our study we will also try to find out if and how the policy instrument theory can be used to analyse long-term care and social support systems. At the same time we will also see if the policy instrument theory itself needs to be adapted (scientifically theoretically relevant).

#### **Assumptions**

What is meant by Long-term Care and Social Support?

In general this study will focus on the long-term care and support systems of different countries. There is no one definition of long-term care or social support, but most definitions refer to some general components. The Health Care Institute in Washington DC defines long-term care as 'a variety of ongoing health and social services provided for individuals who need assistance on a continuing basis because of physical or mental disability'. In this study we will offer a less limited view by including also people with psychological problems and those with sensorially handicaps. Services can be provided in an institution, the home or the community, and include informal services provided by family or friends as well as formal services provided by professionals or agencies (Ter Have, 2003). Services can be organized and steered by central, regional or local government.

Why affordability (cost control), quality and accessibility as values to narrow the scope?

The government has to determine for each policy what the purpose of that policy is. In health care in the industrialized world there are some universal goals, based on broadly accepted philosophical principles. Examples are egalitarianism, solidarity and utilitarianism (Lapré 1999). Historical evaluation shows that these philosophical principles do not change much over time, nor differ among European countries. It is the priority that is given to a certain principle that changes over time and between countries. The same is true for the universal goals in organizing health care; only the interpretation of the goals is subject to change. The Organization for Economic Development (OECD) formulates four general democratic objectives. According to the OECD (1992), the main goals in health care are: Universal accessibility, Quality of services, Professional and patient autonomy, Cost control (efficiency and affordability). These objectives mean that there will usually be an extensive legal structure, dominant government role, and considerable 'public' funding to achieve these objectives.

In the policy document of the Dutch Ministry of Health, Welfare and Sports, the 'Zorgnota 2004' the objectives of the health care policy are as followed defined: "Our policy starting point is that people get necessary care of good quality within a reasonable period and against a payable price." The 3 main aims are thus accessibility, quality, affordability. In the Zorgnota 2004 autonomy is not mentioned as a separate issue. It is more or less considered a part of the quality of care. Accessibility,

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<sup>&</sup>lt;sup>6</sup> Geurts distincts between three categories of being scientifically relevant; something can lead to new understandings, new explanation or new clarifications of theories, methods or facts (descriptive).

quality and affordability are thus the important values to consider as starting point for this study. While there is always a trade off between quality, accessibility and affordability all three items are important for our research. Especially when you consider the fact that there might be a shift of the relative priority of the values when developing and implementing the Dutch Social Support Act.

#### Why Denmark, Sweden, Germany and England as subject of the research?

These four foreign countries are interesting because they all differ from the Netherlands in the institutional structure of the health care system and welfare state model. Based on a former study performed by a trainee at the Ministry of Health, Welfare and Sports in which several theoretical models to describe the welfare and health care states were explored, we derived the important aspects to select the countries in our study (Rijkers, 2004). Two aspects are especially interesting to consider when making clear the value of each country for this comparative analysis for long-term care and social support. These aspects are the welfare state model and the long-term care and social support governance model. The first especially plays a role because it determines the amount of government influence on the organization of long-term care and the policy instruments which will be selected. The second because it shows which government level(s) play a role in organizing and determining long-term care and support system. For the comparison of the policy instruments used in the different countries, these criteria seem to give the best diversity as a starting point. Although in the selection of the countries we didn't have enough country specific information to be able to make a distinction between the policy making and operational responsibility for both long-term care and social support. This led to the fact that the second and third criteria handle both long-term care and social support. The financial responsibility doesn't play a role in our selection of the countries because we didn't have enough information on the criteria at that point yet. At the same time the selection gives preference to cases which best reflect the proposed Dutch situation as can be seen from Table 1.1.1 below. There are also other characteristics, such as stakeholder position and ways of financing<sup>7</sup> of the care, but these play a minor role in our research project.

Table 1.1; Classification of Countries on their Welfare state Model and their Long-term Care and Social Support System

	Netherlands	Denmark	Sweden	Germany	England
Welfare state model (Esping Anderson)	Bismarckian	Scandinavian	Scandinavian	Bismarckian	Anglo-Saxon
Policy making responsibility of long-term care and/or social support	Centralized	Both central and Geographically decentralized	Both central and Geographically decentralized	Centralized	Centralized
Operational responsibility of long-term care and/or social support	geographically decentralized	Geographically decentralized	Geographically decentralized	Functionally and geographically decentralized	geographically decentralized

Source: derived from Rijkers (2004) based on Esping Anderson.

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<sup>&</sup>lt;sup>7</sup> With financing we mean if long-term care and social support is funded based on tax or premiums. For this research the difference between these two is not important while these do not have a direct influence on the manner, with which instruments, the different government levels can steer.

The welfare state model needs some more explanation. According to Esping Anderson, it measures the extent in which differences among social layers are accepted and the degree in which the government considers welfare as a right for everyone (social stratification and decommodification) (Rijkers, 2004). Anglo-Saxon means a more liberal state, in which different social layers are accepted and the market and individualism is encouraged. This is also where the Dutch Social Support policy is heading, although we like to compare ourselves with the Scandinavian countries. Scandinavian means a lot of government involvement and hardly any differences between social classes (equity). As public services are considered right for everybody, anybody should have some level of welfare, independent of the market. Bismarckian corresponds with countries in which there is a higher level of decommodification and a strong social security, where the market is less dominant and there is some level of solidarity but mostly within the different social classes.

While the Netherlands with the introduction of the Social Support Act wants to decentralize much of the responsibility for policy making and operationalization of long-term care and social support. The countries which do have a decentralized responsibility on one of both of these policy fields are interesting to investigate. All the countries in this study have some decentralised form of governance for long-term care and social support. Decentralisation<sup>8</sup> means that responsibilities are transferred from the central to the decentralized level. Geographically means that it is decentralised to regions or municipalities. Functionally means to specific bodies, such as public insurance schemes (=delegation). Sweden and Denmark are in this decentralisation the most far; both policy making and operationalization of care and social support delivery are largely decentralised. England and the Netherlands are the most centralized but a small part of the operational matters are quite decentralized especially for the social support. Despite of this similarity, the organization of long-term care and social support is rather different in the Netherlands and England, as we will see. The Dutch proposal is heading towards more geographical decentralisation.

In former times, the Netherlands would have compared herself with Germany as her guiding country and we still have a lot in common. Nowadays we tend to compare ourselves with the Scandinavian countries, also in the case of the development of the Social Support Act. However, from the above explanation it becomes clear that our proposed situation is not totally comparable with the Scandinavian situation. The comparison works at a decentralisation level, but stops when looking at government influence. Germany and England give in this a better perspective, although these are less and in a different way decentralised. This is also the reason why we put all four countries in our study.

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<sup>&</sup>lt;sup>8</sup> Decentralisation can take form in three ways; *deconcentration* (moving (financial) resources, responsibilities and authority of the central to a local level; but main line management stays at the central level); *devolution* (transfer of responsibilities of a central level to a multipurpose authority, which can be seen as an independent government level with its own legislation, authority and income sources); and *delegation* (semi-autonomous health institutions with delegated authority). The Netherlands, Sweden, Denmark and England mainly have devolution in their decentralisation, while Germany also mainly uses delegation with some devolution.

# 1.4 Research Method

#### **Comparative Framework Determination**

To answer the research questions in the former section a *multi-stage nested comparative analysis* will be made between the five European countries mentioned earlier for a specific status quo. Comparing countries, however, is more than just collecting information about each individual country. In order to connect information horizontally across national boundaries, the information must also be connected on the vertical axis. This means that a comparison must be made on concepts as common points of reference for grouping phenomena that are differentiated geographically and often linguistically (Rose, 1991). Without concepts, information about different countries may be assembled, but we would have no basis for relating one country to another. In Rose's "comparing forms of comparative analysis" (Studies in Public Policy – 1991), he puts up the thesis that systematic comparison makes use of comparable or at least functionally equivalent units of analysis. So, the starting point in this study is the development of a generic vocabulary for classifying the basics of the system. Comparison starts from the logic of a matrix, like the one shown in table 1.2. The columns of the matrix contain the names of the countries, which are arranged side by side along parallel lines. The rows of the matrix list concepts. Two choices should be made: one concerning the countries to be analysed, which has been explained in the former section, and the other the concepts to be utilized.

Table 1.2; General Comparative Analysis Framework

	Country →	Netherlands	Denmark	Sweden	Germany	England
Concept√						

Source: derived from Rose (1991)

The concepts will be defined by answering the first three derived research questions. In our study successively there will be several concepts on the vertical axes. Respectively these will be;

- a number of generic features of the long-term care and support system of each country;
- a set of interesting topics for investigation derived from the basic values of long-term care and support and;
- a policy instrument framework which can be used to compare the use of policy instruments in the different countries.

With the concepts we can build our comparative analysis framework. The answers to the first three research questions will lead to the nested comparative analysis framework for this study. The generic concepts and the specified topics together form the first stage of the comparison. The comparison of the interesting topics on the basis of the instrument framework will give the second stage of the nested comparison. This will result in a framework like the one shown in Table 1.3.

The comparison of countries starts with a description of some *generic features* of each country. An elaboration of these general aspects needs to be part of the comparison because these aspects show the scope of government activities in long-term care and social support, and at the same time give

some historical context. Based on this background, the governmental use of certain policy instruments for certain topics can be described. Which generic features to choose, will be worked out in the second chapter. The first contextual concepts for the comparison will be the result of this step.

Table 1.3; Unspecified Nested Comparative Analysis Framework

Country →	Instrument	Netherlands	Denmark	Sweden	Germany	England
Concept√	categorization <b>√</b>					
Generic concept 1						
Generic concept 2						
Specific concept 1	Instrument concept 1					
	Instrument concept 2					
	Instrument concept 3					
	Instrument concept 4					
Specific concept 2	Instrument concept 1					
	Instrument concept 2					
	Instrument concept 3					
	Instrument concept 4					

Legend: blue = first stage, red = second stage

Next the first research question will be answered. The *specified topics* on which the comparison is based will be explicated in the second chapter as well. The aim of this step is to narrow down research into these specific topics in the perspective of the scope of this research. The determination of the topics will be based on a study of relevant literature and a practical application of the values. The results of this step are the specific concepts on which the comparison will be based.

The topics that result from the first derived research question will subsequently be described and compared for the use of certain policy instruments. To make this comparison possible, an *instrument framework* needs to be defined. Again, this framework consists of concepts. The result of this step, the instrument concepts and the answer to the second derived research question, will be based on a study of relevant literature of policy instruments. In the second chapter, the instrument framework will also be described. These three conceptual steps will lead to the comparative analysis framework presented at the end of chapter two.

# **Filling the Comparative Framework**

All fields in the comparative analysis framework have to be filled; first with the answer to research question three concerning the general features, and secondly the answer to question four concerning the instruments used for every topic of investigation (the main elements of the analysis). The filled policy instrument framework is subject of chapter three of this report.

As can be deducted from the comparative framework this tentative study will mainly be based on qualitative data. We use literature studies to gather information about the long-term care and social support system in the different countries. Part of this information will be based on primary sources and partially it needs to be from secondary sources, because we probably will not be able to get enough information from primary sources solely.

Because there is little structured information available about the *actual use of policy instruments* in the organization of long-term care or support in the different countries, we have partially had to gain new information on this topic. Besides gaining primary and secondary information from literature, field research will be done to obtain additional primary data. The field research consists of participating in some expert meetings ('International Conference on Ageing' in May 2004 and 'Municipalities, Care and Social Support' in June 2004), in sending out questionnaires and carrying out a small sample-survey by using semi-structured expert- or depth-interviews (mainly) by phone based on mainly open questions. The questionnaires will be sent out to the people to be interviewed. The experts will be selected, because they are known for their expertise and knowledge about the long-term care and social support system in their country and they need to be easily reached based on earlier contacts within an international network. In the interviews we will ask for mainly additional information which we could not find in the literature study. The interviews will also be used to elucidate ambiguities.

Besides our own (mainly) telephonic interviews secondary data will be gained from a parallel research trajectory of the National Institute for Care and Welfare which focuses on some specific cases (a person with a mental handicap, a person suffering from dementia, an elderly person rehabilitating from a stroke and a person with severe psychiatric studies). Partially our questions and the case-studies questions in the questionnaires will overlap. While the information in the case-studies will be available after our interviews and literature study we will be able to double check the answers<sup>9</sup>. The resulting data somewhat reduce the lack of critical information.

The largest problem in gaining information is that the interrogated people all look from within their own context and therefore can be very subjective or narrow-minded. Another form of bias can arise on the side of the interpreters. This makes interpretation of the data difficult. By using different sources to gain information and by interpreting it with more than one person, we have tried to make the information more valuable and less dependent of the interpretation of the source/receiver. By explicitly describing all the steps we took, we try to make the study more valid and easier to repeat. It also makes the shortcomings visible for everyone reading this study.

#### Comparison, Confrontation and Explanation

When the information has been gathered the real comparison can be made, which will lead to a number of conclusions with a view to the proposed Social Support Act. The confrontation of the different use of policy instruments will give the answers to derived research questions five and six. Hypotheses will also be formed on which further research may be performed. The fourth chapter of this research will compare the different countries with each other and lead to conclusions. In this chapter general and specific conclusions concerning the development and implementation of the Dutch Social Support Act will be drawn from the comparative analysis.

The last and fifth chapter will summarise conclusions concerning the development and implementation of the Dutch Social Support Act. It will also evaluate this study. It summarizes the answers to the

<sup>&</sup>lt;sup>9</sup> Because we used several research methods (literature study, experts interviews and secondary information from case-studies) we were able to improve the reliability of the data to be analysed (triangulation).

research questions and seeks to answer the central question of this study. The discussion highlights the restrictions and limitations of this tentative study, and presents recommendations for further research.

The division of tasks between the authors in the execution of this research plan is described in appendix 4.

# 1.5 Structure of the Report

In chapter two the comparative model will be developed. It will be based on some general features of each country and the determination of some specific topics of which the use of certain policy instruments can be compared. The instrument framework, which is also part of the comparative analysis framework, will also be part of the second chapter. The third chapter will provide a description of each country. Again this will be divided into some general contextual characteristics, and a section in which the use of policy instruments for certain topics is explained. In chapter four, the countries will be compared and conclusions will be drawn. In the fifth and last chapter these conclusions will be translated into specific lessons which the Dutch central and local government can learn for the development and implementation of the Social Support Act.

# 2. Defining the Comparative Analysis Framework

# 2.1 Introduction

In this chapter a comparative analysis framework will be developed. With the determination of the framework the answers on the first three derived research questions will be given. As explained in the former chapter, the framework will consists of three parts. First the features need to be defined which define the long-term care and social support system and can provide a context to the comparison. Thereafter a set of relevant topics and their operationalization pertaining to the focus of the study will be determined. These will be derived from commonly accepted basic values for long-term care and social support. In the third section of this chapter this second step in the determination of the comparative analysis framework will be elaborated. Following the topics of investigation, the policy *instrument framework* for comparison will be derived from the literature on policy instruments. This will be subject of the fourth section. The fifth section will combine the information of the first three sections in to the comparative analysis framework. In the sixth section the questionnaires for data collection and analysis will be developed based on the operationalizations in the second, third and fourth section and the framework as described in the fifth section.

# 2.2 Determination of the Contextual Features for our Country Comparison

The comparison of countries will start with a description of some generic features of the different countries. This information gives the context of the long-term care system and social support system in these countries. There is no theoretical framework available nor is there a generic framework that is used in former practical international comparisons of health care or long-term care which could be used to determine or arrange the features which will form the context of this research. Although there are several theoretical frameworks to describe welfare state models, governance models and health care systems, as we have seen in the previous chapter, we could not find a model for the description of the long-term care and social support system that could easily be adapted for our research purpose. Even concepts from business administration or policy theory are not available for our purposes. We have investigated different international comparisons, and in each comparison different aspects were described. The largest lack is that frequently the described features are of a different order. The comparisons describe, for example, target group determination and juridical basis at the same level as something as specific as the needs assessment organization (if there is any). As a result of this lack, we have developed a simple structure in which the important general aspects and important contextual factors for this study can find their place. Partially these come from former descriptions of long-term care systems and partially we have designed them on a common sense basis. The general concepts are:

- · Definition of long-term care and social support;
- Objective of long-term care and social support;
- Target group;
- Long-term care and social support arrangements;

- Legal framework and financing;
- Actors.

The first four concepts are important because these give information about the availability of common denominators for the comparison. The structure of health care organization is mainly related to the health policy objectives of a country<sup>10</sup>. The political policy objectives reflect prevailing notions of ideology, culture, tradition, general ethics and history. In turn, these ideas and perspectives determine the division of responsibilities between society and the individual, between government and the market, between community and individual risk, and between public and private funding. The underlying hypothesis is that if there is a difference in these concepts, this will also result in different outcomes when the set of policy instruments used will be compared. An aforementioned policy concept, for example, has a major impact on the management of the long-term care and social support sector. More dominance of government often leads to state-run institutions and state-employed professionals. Another example can be given when you consider that when in a certain country the objective of freedom of choice is emphasized, this will probably lead to the use of a diverse set of instruments on delivering choice supporting information. At the same time these questions give the delineation of what is part of the long-term care and social support package and what not. Because we suppose that not all policy instruments will work for all arrangements, it is important to get clear what arrangements are parts of the country definition of long-term care and support and which are not.

The last two concepts, mainly give information about the operation and functioning of the long-term care and social support system. The hypothesis is that the legal framework and the roles of the different actors bring about a preference for the use of a certain set of policy instruments. The legal structure gives the foundation of all aspects of health care policy. The political notions and history predominate in terms of the organization of the financing system (e.g. taxation or social health insurance), the level of funding, the way available funds are collected and distributed and the way in which cost-sharing schemes for consumers are set up. In all these instances, choices must be made. If the government is legally obliged to deliver care instead of the possibility to decentralize this responsibility to another government layer, this will lead to a different use of policy instruments.

# 2.3 Determination of the Topics of Investigation for our Country Comparison

In this section the topics of investigation will be determined. A well-thought out determination of topics can be of great help when performing the study. Basically the determination of the topics of investigation is dependent of several aspects. At first it is recommended if the topics of investigation are in line with the governmental objectives, otherwise the results of the comparison will not lead to recommendations which are useful and desirable for government. For example, if quality of care is not an important policy at all, then there is also no need to take quality standards, which are a derivate of quality, as a topic of our study. To define the topics in accordance with the objectives of government

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<sup>&</sup>lt;sup>10</sup> The long-term care system is also related to all sorts of historic events, which gave shape to the system. We will not focus on these separately, as these did influence the current policy objectives and, thus, by describing the objectives and main features history will automatically be taken into account.

policy seems a trivial characteristic, but this characteristic gives us a reason to make a distinction between 'important and relevant' indicators and 'interesting' aspects. In this study we will therefore only focus on the important and relevant aspects. There are also some practical aspects which need to be taken into account when determining the topics of investigation. The chosen items need to be limited in number and for all people interpretable in a similar way (clear and consistent). If not, this will affect the information gathering, in the way that it makes it more difficult because manipulation of data will more easily show up. There is also an advantage when using well-known concepts, for example, it will cost less time and effort to collect the desired information especially while it is more recognizable for the people who need to deliver the information. On the other hand when adding up to much items in the comparison, this can make the information gathering time consuming and there is the risk that people get lost through all data. All these aspects are summarized in table 2.1 and will be taken into account when we determine the topics of investigation in section 2.3.2.

Table 2.1; Characteristics on which each Topic of Investigation will be selected.

Characteristic	Explanation
In accordance with the policy objectives	To investigate items that are not considered to be important for the research objective is useless
Concisely and limited number	To ease the information-gathering and limiting the risk of getting lost in the data.
Clear, recognizable and consistent definition of the topics	To prevent manipulation, to make items easier comparable and to give interrogated people a clear understanding of what information is aimed at, which eases the data collection and makes it more reliable.

# 2.3.1 Basic Values and Policy Objectives in Long-term Care and Social Support

To determine the topics in accordance with the objectives of the government policy, we first need to answer the question: 'How does the government wants to steer and control long-term care and social support system in the future? In the past, the existing detailed supply-led system of law and legislation stipulated the steering of the government to a great extent. In the Netherlands the government leaves as much freedom in the organization of care as possible to parties in the field (customers, care providers and insuring companies). Although in some respect the government is tightening the role of private providers. The government has two mutually coherent tasks here: first, monitoring the objectives which belong inextricable to the responsibility of the government: the affordability (cost control), accessibility and quality of the long-term care, and second, to create such conditions that the field parties can realise these objectives as much as possible by themselves. Thus in order to derive the topics on which government will set conditions, it is important that we first explain what is meant by the values of quality, accessibility and cost control.

#### **Accessibility**

The OECD and the Ministry of Health, Welfare and Sports in the Netherlands define accessibility as care that must be available for everyone in need at the right time and at the right place. Accessibility refers to the existence of physical, financial or other barriers for the use of the health services. There

are three forms of accessibility<sup>11</sup>: financial, geographical and social-cultural accessibility (Pomp, 2002). Financial accessibility concerns minimal services for everybody in need for a reasonable fee. An important underlying principle of this form of accessibility is solidarity, a just distribution of wealth. Geographical accessibility means an even spread of the medical services over the countries or municipal territory. This goal is especially important in large countries with a varying degree of regional population density, as is the case in Sweden. The last form of accessibility is the social-cultural accessibility. This means that care or support is accessible for all sections of the population.

# Quality

Quality is a complex term. Everyone has his own perception of quality. Nevertheless there are some definitions of the concept. The OECD uses the definition of the International Organization for Standardisation (ISO): 'quality is the extent in which a product, process or service meets the requirements that were stated from the consumer's goal' (Pomp, 2002). The consumer, not the government, is the key player in this definition of quality. In the Zorgnota 2004, quality is related both to medically substantive aspects and to connecting to the wishes of the patient. Thus patient autonomy in the Netherlands is part of this definition as well. According to the OECD, there are two important types of autonomy in health care: autonomy of the provider and autonomy of the user. Autonomy of the user is usually translated into freedom of choice. Autonomy of the provider usually concerns a physician's autonomy. A physician's autonomy is largely at stake in hospitals and less important in the long-term care and social service organization. Therefore in this study, we will only consider patient autonomy as a part of quality. Because the definition of quality in the Zorgnota 2004 also refers to norms of good clinical practices, innovation is part of this dimension as well.

#### Affordability

The OECD, speaking of cost control, and the Dutch Ministry of Health, Welfare and Sports, speaking of affordability, approach the cost aspect a little differently, but when considering the underlying principles both organizations mean exactly the same. According to the OECD, cost control concerns efficiency and affordability. Efficiency can be defined as 'reaching your goals/output with a minimal use of available resources' or 'reaching a better goal/output, with the same amount of available resources'. Efficiency concerns the ratio between costs and outputs<sup>12</sup>. Efficiency is related to affordability. The goal is to keep long-term care or support affordable to government, patients and the whole (local) population. According to the Dutch Ministry of Health, Welfare and Sports, affordability is pursued both on a micro and on a macro level. The micro level has to do with an efficient functioning of markets. This efficiency knows three aspects: technical efficiency (no waste, exploitation of scale advantages, and synergy impact), allocation efficiency (the market provides optimally in price quality proportion desired by the caretaker), and dynamic efficiency (sufficient product and process innovations). Macro affordability has to do with a mastered development of the macro costs that must lead to keeping care

<sup>11</sup> Accessibility in terms of waiting times is determined as a capacity problem. Capacity is dependent on financial means, therefore it needs to be taken into account as part of affordability.

<sup>12</sup> Through the VRTB (Very Beleich accession to the beleich accession.

<sup>&</sup>lt;sup>12</sup> Through the VBTB (Van Beleidsbegroting tot beleidsverantwoording) operation the Dutch government tries to obtain information about the ratio between costs and outcomes, although this till now has not led to the desired results.

payable also at an individual level. In this study affordability will mainly be seen as whether the responsible authorities, central and/or local governments can afford it. The trade off between the affordability for responsible authorities and for citizens or users is evaded in this study, by considering the affordability for the clients as part of the accessibility definition (financial accessibility). Only when we will be discussing the user fees, eligibility and package limitations the financial accessibility shows up. Mainly we will focus on governmental affordability.

# 2.3.2 Determination of Topics of Investigation

The practical translation of basic values into the topics of investigation is a difficult task. This has mainly three reasons. The first reason is because the basic values will easily conflict with each other. For instance, quality of services and cost control can conflict. An efficient way of organizing care does not automatically mean that the quality of care is of a high standard. Governments need to compromise. It is always been a trade off between quality and accessibility against affordability. This makes the dividing line between the values and the topics that will support a certain value extremely hard to define. The setting of goals is extremely difficult for a government because all three values affect government responsibility, while for individual care providers and clients 'cost control' is a minor issue. For the latter only accessibility and quality are interesting! As we will see later on in this section, this makes it hard to find one model in which the use of policy instruments can be compared while for the different items the starting points differ. For quality, governments set the conditions while for cost control usually there is coercion and more direct action!

The second point is that while there may be universal agreement about the main goals to be achieved, this does not mean that the opinion about how these goals may be reached is agreed on. Nor is agreed on what the order of priorities between goals should be. The translation of these goals into a possible policy instrument mix may vary for different stakeholders (for example provider organizations, user organizations, government etc.) and among countries as we will see in the next chapter. The same is true for defining the important topics on which government needs to set conditions. This makes the comparison proposed in this study interesting, but makes it also difficult to select the important topics. The same is true considering the fact that usually not one single topic will lead to the preservation of a certain value, but a set of related topics may do so. Thus it is not right to attribute preservation to a specific topic.

Third, the selection of the topics based on one's own country status-quo or policy objectives may lead to the fact that one overlooks certain interesting topics in the countries to be compared. The determination of the topics under investigation is then biased, because we are looking at topics which we determine as important in the Netherlands; these however may not be that important in the other country. Although this is a huge problem, we will accept this limitation and we will derive the topics of investigation from the *Dutch current situation* and the *proposed Social Support Act*. However we will take into account interference of individual values and the fact that sometimes it is only possible to look at a topic mix instead of the various topics separately.

In the Zorgnota 2004, there are some specific subjects, which nowadays get a fair amount of attention and contribute to basic values and policy objectives. Concerning quality of service the government takes her role by setting conditions in order for the care providers themselves to increase and maintain the quality of services. Of the subjects related to quality, the Zorgnota mentions surveillance and inspection, uniformity of the actions of health care professionals and uniformity of the ways in which care is delivered. This can be reached by setting up a surveillance organisation, by defining standards of care and by guaranteeing a certain level of professionalism through establishing professional standards or setting criteria, among others. For example, quality assessment and certification are ways in which this can be reached. Because these are not taken into account in the development of the Social Support Act, we have also found it interesting to look at these topics. Quality standards are often and only recently again proposed by political parties, but never survived in the Netherlands. It is thus interesting to find out how different governments take their responsibility in the quality area. These will therefore be part of the analysis. There are also a lot of quality related aspects such as internal audits, inter collegial reviews, visitations, care providers admissions among others, which could be interesting topics as well, but as we need to narrow our study to a restricted list of items these are left out. As we will see later, except for the latter, these usually are handled by government in a similar way as the quality standards and innovation.

Patient autonomy is important, especially looking at the client side of quality of care. In the Zorgnota, patient autonomy will be stimulated through choice supporting information, transparency, client support systems (e.g. by the Dutch MEE-organizations), client satisfaction measurement, right of complaints, encourage the development of resident committees and participation. All these should be interesting topics for our comparison because all of them are not described as a performance field of the Social Support Act. Some topics are not easy to investigate because the information that may be collected will be biased based on a risk of pre-selection or for manipulative information. For that reason client satisfaction measurement is dropped from the analysis. The MEE-organizations are part of the analysis as well, although it is a specific Dutch initiative (elsewhere it is mainly privately organized, except for Denmark).

As was mentioned when quality was defined, *innovation* can be seen as part of the quality of services as well. Because innovation has not been taking into account in the development of the Social Support Act, we have also found it interesting to look at this topic. It is thus interesting to see if and how different governments move in the area of innovation.

As could be seen in the former section accessibility and cost control are directly related to each other. Currently the government has to keep her hand on her pocket concerning expenditures. Cost control, which directly affects accessibility and/or quality, is thus very important. Cost control tools are the use of user fees, charges, needs assessment, package limitations, budget regulations. These are more or less instruments themselves, but largely interfere with each other. This makes the 'all-embracing' concept of 'cost control' part of our comparison.

Informal care is nowadays seen as a way in which costs can be saved. It also refers to the individual's own responsibility not to be dependent on spoon-feeding. The government can stimulate informal care in different ways. As a result of the current discussion, and as informal care support is a major performance field in the proposed Social Support Act we consider it interesting to make an international comparison on this item as well.

The list of topics of investigation which can be derived from the above description consists of:

- Quality standards;
- Quality Assessment;
- Inspection;
- Professionals;
- Innovation;
- Transparency;
- Complaints organization;
- Residents' committees and participation;
- Choice supporting information;
- Cost control:
- Informal care.

# 2.3.3 Operationalization of Topics of Investigation

In this section the operationalization of the topics of investigation will be given. For every topic we will describe what is exactly meant with the topic and what aspects therefore are important in the following analysis. More specific the scope of the subject is defined. This is important because it will delineate the aspects which will be part of the analysis, and therefore the frame of research within the literature study and interviews, and which items will be left out. At the same time it more or less gives the range of options/elements that are considered to be part of the topic or not. For the operationalization we used the Dutch frame of reference mostly formalised in the various policy documents and statements of the Dutch Ministry of Health, Welfare and Sports (such as Zorgnota 2004, Landelijk Actieprogramma Kwaliteit, documents on performance indicators and informal care). This is often also the international frame of reference. Sometimes, however not all aspects which are mentioned in the policy document are used in the operationalization. This is to limit the scope of the thesis. If we use something specifically or something different from the Dutch frame of reference this will be mentioned explicitly.

For example concerning the quality standards the operationalization is made by designing a  $4 \times 3$  matrix in which on the horizontal axis the parties that agree on the standards are described (italic in the example below) and vertically the scope or subject of the standards (bold and italic below). All other topic will be operationalised in a similar way, although we will not explicitly pronounce them.

In the Netherlands we normally define quality standards as agreed upon standards by *government*, professionals, insurance companies and care and social support providers concerning the **content** and/or the **execution** and/or the **obliged use of guidelines** of care and social support delivered.

Quality Assessment is defined as the tools to assure a certain level of quality of care and services. Common instruments in quality assessment are *quality management* and/or *certification*.

The operationalization of inspection can be described as the fields on which the inspection is directed; measured performance and/or the availability of quality standards.

The professionals-topic can be operationalised on the target group (*nurses* and/or *social support* workers). On the other hand we will focus in this study on *education criteria*, and/or *registration* of professionals and/or subordination to *medical disciplinary board*.

Innovation can be defined as renewal and modernization of long-term care and social support. It often concerns *new concepts for care or social support*, and/or *new technological innovations* and/or *else*.

Transparency can be operationalised by monitoring and publishing facts and figures of long-term care and social support on a *regular basis* or *incidentally*. We specifically are interested in *benchmarking* as a operationalization and/or *something else*.

The complaints-topic can be operationalised by the presence of *official complaints committees*, and/or the presence of a *complaints official*, and/or the presence of an *Ombudsman*.

A residents' committee is committee of patients/clients which participates in the long-term care and social support policy offered by *care providers*. Participation can also be reached by using participation in *government* decisions. The latter is mainly adapted from the English situation.

Choice supporting information enables patients to make a well-considered choice which long-term care and social support provider to choose for the care and support they want. Therefore it can be operationalised as information on the *providers to choose* and/or information about the *care to be delivered*.

There are several tools that can used to achieve cost control. *Price negotiation*, *budget regulation*, *compensation limitations*, *user fees*, *needs assessment* can be discriminated among others. While these are most often used in the health and/or long term care and social support system we will in this study only focus on these items. Therefore the operationalization only focuses on these items successively or a new category *else* (if a specific country uses a substitute).

More in depth the user fees can subsequently be operationalised by looking at the fact if there is a *means testing* and the scope of services where the user fee is applicable (*hotel function* or *else*). Needs assessment needs to be operationalised on different levels; by considering the fact if there is a *standardized assessment* (standardized assessment *list* or *procedures*), the fact if *informal care* is taken into account in needs assessment and the organization or *person that is performing the needs* assessment (*social worker, insurance board, nurse, healthcare professional*)

Informal care is provided by relatives, friends and others who are not professionals and who provide this care on a voluntary basis, so they are not employed by a care provider. Informal care can be operationalised by the fact if there is a *financial compensation* for informal carers, if there is a *care leave*, if there is *professional training* for informal carers, if there are *relief and respite facilities*, and/or if there are *informal care organizations*. In the literature about informal care these categories are always mentioned as important items in the whole package of informal care support.

# 2.4 Determination of the Policy Instrument Framework for our Comparison

Now that the topics of investigation have been defined, the next step is to address a framework of the policy instruments used in the organization and steering of long-term care and social support. To generate such a framework is important because it makes country specific information comparable. Section 2.4.1 and 2.4.2 focuses on general theories of policy instruments. In section 2.4.2 the categorization for this research project, the instrument framework, will be defined.

# 2.4.1 Determination of the Suitable Policy Instrument Theory

Policy instruments can be used by governments to influence subjects or citizens or to receive the desired information in order to achieve their specific mix of policy goals. Many books have been written about policy tools used by governments. There are also many ways in laying out government's tools, all differ in perspective, and none of which will be necessarily right. For example De Bruijn & Ten Heuvelhof (1991) distinguish between a narrow (instrument as a thing) or broad (activities as instruments) definition of instruments, while other authors discriminate between direct and indirect policy instruments (Bressers, 1998). In Bressers' definition, direct instruments support reaching the goal without interference of another instrument. Indirect instruments support other instruments. Hood e.a. distinguishes groups of instruments with corresponding characteristics (communicative, economic, legal and organization). Another arrangement can be given by ranking the policy instruments according to the degree of coercion. This, however, is more a combination of categorizations which can be found in the science of social policy, including classifications of Hood (1983), Peters & Van Nispen (1998) and Van der Doelen (1998). A distinction can be made between first and second generation steering instruments. In this division the first generation is defined as unilateral instruments, and the second generation can be seen as multilateral instruments (e.g. agreement, negotiation and networking) (De Bruijn, 1991). In fact, this last categorization can also be seen as a part of Hood's categorization, as we will see later in more detail.

Regarding our central research question what we can learn from the use of certain policy instruments for the development of the Dutch Social Support Act, it is not easy to take the narrow/broad definition of policy instruments as a starting point. The division between tools as a thing or as activities still leaves us with a messy distinction, because both can be true, e.g. needs assessment or surveillance. There will be an ongoing discussion about if something is an instrument or an activity. Besides that and even more important is the fact that this distinction leaves no room for a resolute attempt of the government to influence the actors in a certain way. It is thus just a theoretical distinction. The

distinction between direct and indirect instruments can be dropped as well based on the foregoing discussion; the government wants to reach certain goals in a specific way. Whether this is done directly or indirectly is not important for our research project. Thus at first sight, the classification of instruments with corresponding characteristics gives the best point of departure for our policy instrument framework. Therefore we will further elaborate Hood's theory of policy instruments.

# 2.4.2 Hood's Categorization of Policy Instruments

First, Hood distinguishes between government's tools for detection and its tools for effecting. Detectors are all the instruments the government uses for taking in information. Effectors are all the tools that a government can use to try to make an impact on the world outside. Following this first distinction Hood breaks down each group into four other groups. First there are communicative instruments; Hood calls them 'Nodality based'. This group concerns the ability to transfer information. Nodality equips a government with a strategic position from which to dispense information or to draw in information for no other reason than that the government is in the centre. The limiting factor is credibility. If a government loses her credibility, she will no longer be able to traffic in information. The second group is the economic instruments; Hood calls them 'Treasure based'. Treasure gives a government the ability to create financial incentives to influence outsiders or to buy mercenaries of various kinds. The availability of fungibility of treasure, or the fact that it can only be used once, is the limiting factor. The third group, is the legal instruments group. Hood calls them 'Authority based'. Authority gives government the ability to 'determine', consisting of order and prohibition legislation. Legal standing limits the use of this kind of instrument. Finally Hood distinguishes the 'Organization based' group<sup>13</sup>, which gives government the physical ability to act directly, using its own forces rather than mercenaries. The limiting factor is capacity (Hood, 1983). By combining the two control mechanisms (detectors and effectors) and four types of resources, eight basic types of tools which government can use when it comes into contact with the outside world are defined. These are schematically presented in table 2.4.1. These instruments will be used in a specific instrument mix for each outcome desired by government.

Table 2.2; Policy Instrument Categorization

Types of resources → Control mechanism ✓	Nodality based	Treasure based	Authority based	Organisation based
Effector				
Detector				

Source: Hood (1983)

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<sup>&</sup>lt;sup>13</sup> For some people organization will be held to be a compound or derivate of nodality, treasure and authority; a subset rather than an element of the same set. However it is treated here because it is perfectly possible to derive nodality, treasure and authority from organisation rather than the other way around. Here is the organization of last resort activities, if it is not possible to steer private partners do act as is desired.

When the categorization is made, it is also relevant to describe in brief what kind of instruments in general and particularly, considering the long-term care and social support, are part of each category<sup>14</sup>. There we would like to mention that the list of instruments mentioned is far from complete. In the next chapter the arrangements will be described for each policy domain.

#### **Nodality Based Instruments; Persuasion and Communication**

Governments communicate to persuade the target population, the users of care, the providers and all other stakeholders to influence the goal achievement in a certain purposeful way. Communication gives the government the ability to adjust, not to control. This is the least coercive type of instrument. Persuasion and communication are based on the transfer of information, like direct notification through lectures, information campaigns, telephone services, research and political debate, among others. Sometimes it has a negative connotation, as it also includes suppression of information, propaganda or deliberate deception. The stimulation of self-regulation can be considered part of this category as well. Protocols and practice guidelines are good examples of self-regulation, and these are frequently used in health care settings (although the development of these can also be the result of the treasure based chequebook-government). Public private partnerships, covenants, (gentlemen's) agreements, cooperation bonds etc. between the government and insurers, called second generation policy instruments by some authors (De Bruijn, 1991), are also part of this category.

# Treasure Based Instruments; Subsidies and Charges

A subsidy is a form of financial support of the government for a specific activity (Van den Heuvel, 1998). A subsidy attempts to encourage certain activities. There are quid pro quo payments in the form of contracts, bounty (open ended). Examples of non quid pro quo payments are bearer directed payments, transfers (gifts) and conduits payments via an intermediary. Subsidies are part of the quid pro quo expenditures of the government. A second form of treasure based instruments is formed by charges. A charge also seeks to influence behaviour in a financial way, but in a negative sense. A charge attempts to discourage an unwanted or wanted activity or to pay for a wanted or unwanted activity! Local taxes, direct payments (for example prescription charges) paid by long-term care or support users belong to this category.

## **Authority Based Instruments; Restrictive Prohibitions and Regulation**

This category corresponds to the common image of regulation. Regulation expands, orders, restricts, or prohibits, options of organization or individuals. Regulations contain rules, if necessary supported by legal sanctions, for influencing the behaviour of organizations and individuals. The group of regulating instruments has become very diverse (Hood, 1983). Certificates, conditional tokens (bonds and guarantees), enablements (licenses, warrants, quotas, coupons, vouchers, (open) permits, exemption certificates), constraints (arbitraments) are examples of tools in this category. Orders are for example special social support regulation; complaint regulation. Prohibitions are building

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<sup>&</sup>lt;sup>14</sup> Hood makes another division within the categories he describes. He distinguishes between tools which act on the individual, on a specific group and blanketed tools acting on anybody. Because our research focuses on the steering of long-term care and social support providers and care receivers, there is no need for further elaboration of this second division.

regulations; product specifications; price fixation and budget regulation; compulsory certification. The use of the law as an instrument for social change has changed the character of the law. More often than before laws only contain a framework or frame within which goal-targeting can developed. When self-regulation is perceived by 'conditional self-regulation', where government sets up a framework in which self-regulation has to fit. It is part of this category as well. So the government sets rules for making rules. (Semi-) voluntary quality assessment, certification, benchmarking (on performance indicators) by service providers also belong to this category.

# Organization Based Instruments; Public Ownership

Public ownership concerns the goods and services provided by government, such as marking products, storage and custody, transportation and distribution, processing. Another distinction can be made between individual, group or at-large treatments. This not only includes public enterprises (processing), such as publicly owned care homes, but also organisations belonging to the governmental bodies. Surveillance organizations and needs-assessment organizations when executed by governmental bodies can be seen as examples of marking.

# 2.4.3 From Hood's Policy Instruments to a Policy Instrument Framework

With regard to the above detailed description of policy instruments and our research questions, some points of attention can be distinguished and some decisions need to be taken.

#### Effectors alone...

The most remarkable is probably the distinction between effectors and detectors. In our research design, we did not focus especially on acquiring information for steering, the detectors-side of Hood's model. This is not an explicit part of the proposed Social Support Act either; however, a discussion if it should not have been taken into account or not could have been interesting in our opinion. Also based on practical reasons, the detector side will not be part of this analysis. A brief investigation of the detectors in the different countries resulted in a jumble of impressions and ways the detector side is organized. For an analysis this could not easy lead to universal conclusions. Thus to narrow the scope of the research project, the detectors will be left out<sup>15</sup>.

# **Steering inside Government or to Outside Agencies**

Now the instrument categories have been defined, a new difficulty can be distinguished. This is the fact that there are varying degrees of compulsion. For example, needs assessment or benchmarking can be done voluntarily, by local groups, or by local authorities as part of good practice, or by local authorities because they are advised to do so by central guidelines, or by local authorities because they are subsidised to do so by central government, or by local authorities because they are forced to do so by central government, or simultaneously in several of these modes. To avoid the messiness which arises, we will only focus in this study on the steering from the

<sup>&</sup>lt;sup>15</sup> If for example the free game of negotiations between care providers and care insurers will lead in certain regions to the decrease of care supply below a certain level, the government needs to react. To follow such developments monitoring needs to take place.

government to an outside agency (subject or citizen). This steering can take place directly from local (or regional) government to the outside agency, from central government to the outside agency or indirectly from central government to the outside agency through regional or local government. This distinction is important while in the latter situation it is central government which determines the scope of the activities and tools which the local government can use to control and steering the outside agency. If central government decentralises activities without leaving the local government the elbowroom to act, the desired objectives never will be obtained (e.g. unfounded mandates).

### **Different Government Levels; Different Actions**

However, for the aim of the study, to learn for the development and implementation of the Social Support Act, which is directed towards more responsibilities for the local government, it is important to make a distinction between the different government levels in the comparison. The information, concerning which government level uses a certain policy instrument, needs to be taken into account in the comparative framework. As this adds another stage (level/nesting) into the framework, the simplest way to add this stage is possibly to tag each instrument that is entered into the model with the tag 'centrally launched', 'regionally launched' or 'locally launched'.

## **Self-regulation as Part of the Instrument Framework**

As is described in the former section if actions are done voluntarily by a private actor, this will be part of self-regulation. Depending on the self-regulation as a result of persuasion, of monetary incentives, of conditioned self-regulation or totally voluntarily, it will be differently implemented in the model. The first three manners will be described respectively as 'nodality based', 'treasury based' and 'authority based'. The description of self-regulation will only be textually visible, although the category on which it is based is described in the framework.

Altogether this will lead to the following model for the instruments:

Table 2.3; Policy Instrument Framework

Countries →	Netherlands	Denmark	Sweden	Germany	England
Types of resources ↓					
Nodality based	(central/regional/local)	idem	idem	idem	idem
Treasure based	idem	idem	idem	idem	idem
Authority based	idem	idem	idem	idem	idem
Organization based	idem	idem	idem	idem	idem

# 2.5 Determination of the Comparative Analysis Framework

The comparative analysis framework can now be put together. This results in the following scheme for comparison:

Table 2.4; Policy Instrument Framework

Country →	Instrument	Netherlands	Denmark	Sweden	Germany	England
Concept√	categorization <b>↓</b>					
Definition Itc & ss						
Objective Itc & ss						
Target Group	$\sim$					
Arrangements	$\sim$					
Legal Framework						
& Finance						
Actors	> <					
Quality Standards	Nodality based	(central/regional/local)				
	Treasure based	(central/regional/local)				
	Authority based	(central/regional/local)				
	Organization based	(central/regional/local)				
Quality	Nodality based					
Assessment	Treasure based					
	Authority based					
	Organization based					
Inspection	Nodality based		1			
	Treasure based					
	Authority based		1			
	Organization based					
Professionals	Nodality based					
	Treasure based					
	Authority based					
	Organization based					
Innovation	Nodality based					
	Treasure based					
	Authority based					
	Organization based					
Transparency	Nodality based					
	Treasure based					
	Authority based					
	Organization based					
Complaints	Nodality based					
	Treasure based					
	Authority based					
<b>5</b>	Organization based		-			
Residents'	Nodality based					
Committees	Treasure based		1			1
	Authority based		1			1
Ohaiaa	Organization based		1			1
Choice	Nodality based					
Supporting Information	Treasure based		<del>                                     </del>			+
miormanon	Authority based Organization based		<del>                                     </del>		+	+
Coot Control			<del>                                     </del>		+	+
Cost Control	Nodality based				-	+
	Treasure based Authority based					
			<del>                                     </del>		+	+
Informal Care	Organization based Nodality based				-	+
miormai Care			<del>                                     </del>		+	+
	Treasure based					
	Authority based		<del>                                     </del>		+	+
	Organization based		1	1		

# 2.6 Plan for Data-gathering, -processing and -analysis

Now all the concepts are operationalised in de above sections<sup>16</sup> the next step is to draw the questions at issue for the data analysis. These questions are needed for the content analysis of the literature study and as a starting point for the interviews. Therefore we had to develop a questionnaire for the data analysis and the interviews. The questionnaire for the content analysis is a derivate of the above scheme in combination with the operationalization of the general concepts, the topics and the different instruments which are part of Hood's four instrument categories. This questionnaire is described in Appendix 1. The questionnaire for the interviews is derived from the first questionnaire but will just ask for additional information which we were not able to find in the literature study. The interview questions will also be used to elucidate ambiguities. The interview-questionnaire is described in Appendix 2. Based on these questionnaires the schemes of comparison which will be used in the analysis in chapter 4 are developed.

The general context questions are very specific. Based on the description of the concepts in section 2.2 contextual questions are derived. These are described in Appendix 1.

Mainly we followed the following line of questioning for each topic:

- An existence-question;
- Several content-questions;
- One or more content-questions concerning distinction long-term care and social support;
- An involved government level-question;
- Several questions focussing on the combination of used instruments on a specific government level.

As a result of the above described line of questioning, the questionnaire for content analysis for the quality standards exist of the following questions:

- Are there any national quality standards in the area of long-term care and social support in the country under investigation? (existence-question)
- Do these standards reflect the content of the care and social support and/or the execution and/or the use of guidelines regarding the quality of care and social support? If so (as a check), what do these national standards contain and/or measure: level of services, way of deliverance, quality of output, quality aspects on the professionals delivering the care of something else? (content-question)
- Are these quality standards defined by government, professionals, insurance companies and providers? (content-question)

<sup>16</sup> The general contextual concepts are operationalised in section 2.2, the specific topics of investigation are operationalised in section 2.3.3, the instruments based on Hood are operationalised in the subsections in section 2.4.2 and 2.4.3 as far as it concerns the different government levels on which this study focuses.

- Do the standards reflect long-term care or social support? For example, products which are not really care (like meals on wheels etc.), are they part of the quality standards as well? (content-question concerning distinction long-term care and social support)
- Are these standards implemented by local / regional or central government? (involved government level-question)
- Which instruments does which government level use to stimulate/implement/guarantee the
  quality standards? For example, are there any financial or other sanctions when quality does
  not meet the quality standards or are there any subsidies or other monetary stimuli for
  improving the quality on a local/regional/national level? (combination used instrumentsquestion and involved government level-question)

Besides the questions which are important in relation to our research design, we sometimes also asked for some background information. All other topics lead to similar lists of question. The total list is described in Appendix 1.

# 2.7 Summary

In this chapter we defined the comparative analysis framework. We determined the contextual features and the topics for investigation for the country comparison. Subsequently we determined the framework with policy instruments based on the theory of Hood. As a third step we operationalised the contextual features, the topics for investigation and the instruments and finally we put the framework together.

# 3. Long-term Care and Social Support in Five European Countries

### 3.1 Introduction

In this chapter the main information of the five European countries and their long-term care and social support organization are described. The general characteristics of the long-term care and social support system (as defined in section 2.2.) and the specific topics which serve as starting point for our study (as defined in section 2.3) are described in this chapter. Successively The Netherlands, Denmark, Sweden, Germany and England will be described. The country-specific information is based on literature study, sending out questionnaires and performing interviews. Before entering the country-related sections, we will give account to our used data-gathering methods.

# **Summary of Used Methods and Techniques**

The information is based on extensive literature study. We used primary sources; we researched the text of different laws (such as Algemene Wet Bijzondere Ziektekosten (AWBZ), Wet Voorzieningen Gehandicapten (WVG), Social Service Act (SOL), Pflegeversicherunggesetz (PVGS)), documents (such as Zorgnota, The NHS-plan, Local Charters), annual reports of national and international government bodies (such as European Union, Organisation for Economic Co-operation and Development) and homepages of the concerned ministries in the different countries as well as the homepages of several local authorities. Besides primary sources we used secondary sources, by mainly visiting the homepages of long-term care and social support related organization such as patient organization, care providers in which government policy statements more often were translated. In addition to this we researched a number of compilations of country descriptions about long-term care and social support (such as 'Providing Integrated Health and Social Care for Older Persons' (Leichsenring, 2004). We also investigated several research reports on long-term care and social support in the different countries (such as Ecorys-NEI (2003)). Most literature is describing the structure of the different long-term care and social support system. The available information from the literature study will be analysed on the basis of the questionnaire as mentioned in section 2.6 and described in Appendix 1.

Besides that, supplementary information is gathered by (explanatory) open questionnaires answered by experts (semi-structured expert interviews) from the four European countries (see Appendix 2). The experts were selected, because they are known for their expertise and knowledge about the long-term care and social support system in their country and they need to be easily reached based on earlier contacts within an international network. The list of interviewed people is described in Appendix 3.

Besides our own (mainly) telephonic interviews secondary data is gained from a parallel research trajectory of the National Institute for Care and Welfare which focuses on some specific cases about clients in long-term care and social support. Because the case-studies came about after we almost finished our thesis, they were just used to double check the information already processed.

Nevertheless not all questions for all countries have been answered as extensively as we hoped for. Moreover countries differ, so that some elements in some countries do not occur or only occur to a very restrictive degree. As a result, this report only summarizes the information that is interpretable in a similar way or that offered relevant and interesting starting points. At the end of the chapter the findings are grouped.

### 3.2 Netherlands

# 3.2.1 General Information on the Dutch Long-term Care and Social Support System

# **Definition of Long-term Care and Social support**

In the Netherlands there is no formal legal definition of what long-term care and social support is. Long-term care is usually defined as everything that is paid for by the General Exceptional Medical Expenses Act (AWBZ, Algemene Wet Bijzondere Ziektekosten), the Welfare Act (WW, Welzijnswet) and the Act on Services for the Disabled (WVG, Wet Voorzieningen Gehandicapten). The entitlement is based on a need for care. In the policy documents of the Social Health Insurance Council (CVZ, College voor Zorgverzekeringen) concerning the Exceptional Medical Expense Act, you are entitled to Long-term care if the need for care is; continuous, systematic, long-term and multidisciplinary. This is not a legal definition but it is generally accepted as the definition of term long-term care. The entitlement on long-term care is not based on a formally described minimum level of care needed nor a minimum duration.

# Objective

The aim of the Exceptional Medical Expense Act is People get necessary care of good quality, within a reasonable period and against a payable price. The aim of the Act on Services for the Disabled is to make it possible for the elderly and disabled to live independently as long as possible. The aim of the Welfare Act is to organise regulated supplies for self-help groups, people with problems of social exclusion and individual support for restoring the balance within people's personal life.

#### **Target Group**

The target group of long-term care and social support concerns:

- Elderly;
- Mentally disabled;
- Physically disabled;
- Sensorially disabled;
- Psychiatric patients;
- · Chronically ill.

#### **Care Arrangement**

Concrete care supply<sup>17</sup> includes:

AWBZ<sup>18</sup> nursing homes/care homes; **AWBZ** crisis admission; • **AWBZ** protected living; day relief(social re-activation); **AWBZ** night relief; **AWBZ** short term admission; **AWBZ** home care/house help; **AWBZ** AWBZ psychiatric care; WW meals; social prevention; WW Person oriented guidance; **AWBZ** Home adjustments; WVG WVG / AWBZ / Sickness funds Transportation services; Alarm devices; WVG

The supplies are mostly in kind or personally bound budget (financial compensation).

#### Legal Framework and Funding

Aids.

The long-term care in the Netherlands is for the largest part formally described in the AWBZ, the Act on Services for the Disabled and the Welfare Act. All Dutch legal citizens are insured by law; the AWBZ is a social insurance by right. This means that everyone who meets the criteria laid down in the law is able to claim.

WVG

On 1 April 1994 the WVG became into effect. The WVG is based on a care duty. This means that claimants (people with a confirmed need for care) are entitled to supplies of the WVG. The WVG helps local authorities to provide facilities to people with limitations to enable them to live an independent life. The WVG has a decentralised regime within which local authorities have been given the responsibility to provide "customised care". This can result in differences between municipalities. The welfare act works differently and has no (enforceable) care duty. This law regulates the responsibility of municipalities to organise regulated supplies for certain groups under that law.

The funding of the AWBZ is covered by a compulsory premium, which is levied together with income tax and then transferred to the central fund of AWBZ. In 2003 the premium was 13,25% of taxable income. This fund is supervised on the central government level by a statutory body, the CVZ. This Council, in turn, distributes the funds to its statutory agents, the Sickness Funds. The Welfare Act and

<sup>&</sup>lt;sup>17</sup> In the AWBZ the care people are entitled to is defined as: personal care, house help, nursing, treatment, stay, social support, person oriented guidance

person oriented guidance.

18 These are the laws in which the arrangements are based. The explanation of the laws is subject of the following section 'legal framework'

the WVG are both tax funded by the central government. The Welfare Act is financed with a goal allowance within the municipalities' budget. The Act on Services for the Disabled is part of the budget of the central government as well.

There is a lot of attention to individual patient's rights in the Netherlands. In the Medical Treatment Agreement Act (WGBO, Wet Geneeskundige Behandel Overeenkomst) rules are laid down how (medical) professionals should treat their patients and how they have to make an arrangement with them. A second law which rules patient's rights is the Act on Special Admission Psychiatric Hospital (BOPZ, Bijzondere Opneming Psychiatrisch Ziekenhuis). This law is not only meant for psychiatric patients but also for the mentally disabled and (older) patients suffering from dementia.

#### **Actors**

Four actors play a role: the central government, the local governments, the Administrative Care Offices (Zorgkantoren) and the private providers.

## Policy Making Responsibility

The Minister of Health, Welfare and Sports is responsible for the accessibility, quality and cost control of long-term care and social support in the Netherlands.

## **Operational Responsibility**

The national government is responsible for execution of the long-term care (AWBZ); the local authorities are responsible for well being and mobility. The execution of the Welfare Act and the WVG therefore are decentralised to the municipality. The central government passes on the responsibility for care mainly to the Administrative Care Offices. The Administrative Care Offices board out services by means of contracts to the non-profit and private sectors. Under the AWBZ system, patients never receive a bill; payments are made directly to providers according to regulations.

## 3.2.2 Dutch Policy Instrument Mix arranged on Long-term Care and Social Support Topics

#### **Quality Standards**

In the Netherlands there are four national laws that regulate the quality of care: the Care Institutions (Quality) Act (Wet Kwaliteit Zorginstellingen), the Individual Health Care Professions Act (wet BIG), the Medical Treatment Agreement Act (WGBO) and the Right of Complaint for Clients of the Care sector (WKCZ, Wet Klachtrecht Cliënten Zorginstellingen). Those four laws form a framework with which care providers are encouraged to deliver quality of care. These laws do not contain national quality standards; the Care Institutions (Quality) Act is enabling legislation and speaks of 'responsible' care. This means that care must be provided in an effective, efficient and patient-oriented manner. This Act stipulates that in the first instance the care providers themselves are responsible for formulating standards for quality care (field standards). So far, they have been hesitant to do this and there is no incentive or sanction to force them.

### **Quality Assessment**

Care providers are encouraged by the Care Institutions (Quality) Act to work with a quality management system and to obtain a quality certificate, but on a voluntary basis. The central government subsidizes the development of quality assessment and the development of certification schemes. In practice this means that 0,5% of Dutch long-term care providers have a certificate.

#### Inspection

The Health Care Inspection (IGZ, Inspectie voor Gezondheidszorg) supervises the management of the health care system and the quality of the care it provides. It reports and issues recommendations to the government and the care institutions. The IGZ is part of the Public Health Supervisory Service, and is organised on a national level. The inspection supervises all fields of (health and) long-term care. The IGZ is an autonomous organ, so they can criticise the Minister of Health, Welfare and Sports. The inspection focuses on everything that is 'care', excluding welfare institutions. They assess the quality of health care on the basis of (client supportive) legislation, field standards and the state of the art. The Inspection is based on the Health Care Act (Gezondheidswet).

#### **Professionals**

The Individual Health Care Professions Act regulates the provision of care by professional practitioners, focusing on the quality of professional practice and patient protection. The Act focuses on individual care, i.e. that is aimed directly at the individual. This means that this act doesn't concern house helpers, informal carers and social service workers. The Health Care Professions Act concerns the medical disciplinary boards for nurses. The primary aim of the act is to create conditions necessary for fostering and monitoring standards of professional practice in individual care. Secondly it has introduced a system to protect the titles of a limited number of professional groups (Schrijvers, 1997). The Dutch government subsidizes the development of professional standards and procedures. The professionals largely regulate themselves.

#### Innovation

Innovation is often a public-private partnership in the Netherlands; the initiative can come from both sides. The main effort of the national government is subsidizing public-private partnership or starting a programme for instrument development. Knowledge centres are private institutions partly financed by the Ministry and partly financed by care providers. In general, they work programme-based. Investment in innovation is the lowest in welfare and social services, in long-term care business process redesign is an important issue.

## **Transparency**

All forms of transparency are organised on a national level. Every year The Dutch Ministry of Health, Welfare and Sports publishes a report concerning the long-term care in cooperation with the care-providers. Currently the Dutch Ministry is developing performance indicators, based on the Balanced Score card, but they have not yet been put into practice.

There is no national data bank on prices or quality of care providers. Benchmark information is only available on an authorized level, cooperation of care providers is on a voluntary bases. There is no benchmark or public quality and price information in the welfare and social service.

#### **Complaints**

The Dutch Act for the Right of Complaint for Clients in the Care sector (wet Klachtrecht Cliënten Zorgsector) deals with the possibility to appeal through official complaints committees. This means that care providers have a duty to organize a complaints committee and a complaints registration. The welfare providers aren't obliged to organise complaint committees. There is no national data bank for complaints.

#### **Residents' Committees and Participation**

Residents' committees are provided for in a law called the Care Institutions Clients' Right to Participation Act. This law rules that all intramural and extramural care providers (excluding welfare or social service) should have a residents' committee. In practice this means that in general home care organizations, nursing homes, homes for the elderly and institutions for the disabled and psychiatric patients have client participation organized in a residents' committee. A few national private organizations give support to residents' committees. Those national organizations are subsidized by the Ministry. On a local level there are Regional Patients platforms which speak on a local and national level with the government and try to have influence on health care and long-term care policy.

## **Choice Supporting Information**

There are no guidelines in the Netherlands concerning choice supporting information for long-term care providers. The Ministry of Health, Welfare and Sports feels that it should be available, but up to now it has not been arranged. Client satisfaction is measured by private organizations that get subsidies for it, but the cooperation of care providers is on a voluntary basis.

#### **Cost Control**

In the Netherlands several methods are used to control costs and at the same time still guarantee a certain level of accessibility of long-term care and social support delivery:

- Price negotiation with providers for the care delivery;
- Budget regulation;
- Compensation limitations;
- User fees:
- Needs assessment;
- Support for informal carers.

#### Compensation Limitations

There is the possibility of compensations of user fees by tax refunds. A second option is to apply for special social relief (Bijzondere Bijstand); this is a scheme that enables local governments to give citizens a financial contribution towards costs that are necessary but that in connection with their individual circumstances cannot be paid out of their own income or any financial means they might have. This may also be costs for care services.

## Price Settlement and Budget-regulation

The budget for care institutes and their corresponding tariffs are established centrally, but the institutes are free to determine how their budgets are spent. Care providers get a lump sum budget based on: the number of "beds", the individual patient and basic costs (building, overhead). Home care organisations also get a lump sum budget based on the needs of the individual patient and basic costs. The budget is based on the production agreement made with the administrative care office. In recent years there were no limitations on production in order to reduce the waiting lists. In March 2004 the Ministry of Health, Welfare and Sports put a maximum to the production. At this moment the Ministry is reorganizing the budget system of the AWBZ the effort is to get output pricing labelled on each of the seven functions, as mentioned before (Ministry of Health, Welfare and Sports/EPC, 2002). Prices are set by the national government based on a law called the Act on Tariffs in Health Care (WTG, Wet Tarieven Gezondheidszorg) and set by the National Health Tariff Authority (CTG/ZAio, College Tarieven Gezondheidszorg Zorg Autoriteit in oprichting). This organ determines how the budgets for care institutes and tariffs are fixed. The policy rules must be approved by the Minister of Health.

## User Fees

Insured citizens of 18 years and older residing in intramural AWBZcare (psychiatric) hospitals, care homes, nursing homes, must pay a contribution or user fee towards the costs. There are three kinds of contribution; two of which depend on income with a minimum and a maximum level (home care and intramural care); the third is a fixed contribution (aids). The user fee is collected centrally by a government body (ZBO, Zelfstandig Bestuurs Orgaan).

## Needs Assessment

The regional indication board is accountable for needs assessment; there are about 80 boards in the Netherlands. At this moment the local government is responsible for the budget and the performance they deliver. On January 1<sup>st</sup> 2005 the indication boards become central steered organs. The reason for this is the ongoing discussion about the performance they deliver. The Regional Indication Board (RIO) delivers needs assessment for all long-term care and social support. The National Association for Indication Boards (LVIO) has issued guidelines enabling the regional indication bodies to assess quickly and conscientiously with the consumers in mind.

### **Informal Care Support**

There is no allowance for informal carers; there is the possibility of tax refund and care leave. The Work and Care Act (2002) (WWI, Wet Werk en Inkomen) gives the opportunity for care leave in case of a personal emergency. This arrangement gives employees the right to paid leave in the case of exceptional personal circumstances. It is limited to only a few hours to up to several days (Bertelsmann Foundation, 2002). There are some national private organizations which support informal carers, provide education, take care of respite care. Those organizations are subsidized by the Ministry of Health, Welfare and Sports.

#### 3.3 Denmark

## 3.3.1 General Information on the Danish Long-term Care and Social Support System

#### **Definition**

Denmark has no legal definition of long-term care. The long-term care and social support definition is based in practice on a need for care. Elderly people receive help according to their level of function. All residents in Denmark have direct access to various services if they are unable to cope on their own because of temporary or permanent impairment of physical or mental capacities. The entitlement to long-term care is not based on a minimum level of care needed nor a minimum duration (Socialministeriet, 2004).

## **Objective**

The objective is integrated health and social service. Integrated health and social services imply that the services are provided for all elderly, independent of where they live, by integrated teams of home helpers, home nurses etc. Danish long-term care is founded on the principle of free, equal access to care. The aim is to improve the individual's possibility of living at home or to ease his/her everyday existence and to improve his/her quality of life. This is based on the general principles of ensuring continuity in an individual's life, making use of people's own resources, preserving a person's self determination, and sustaining a person's ability to influence their circumstances. The basic idea is "help to self-help".

#### **Target Group**

In Denmark long-term care an social support concerns:

- Elderly;
- Mentally disabled;
- · Physically disabled;
- Sensorially disabled;
- Psychiatric patients
- · Chronically ill.

### **Care Arrangement**

Concrete care supply includes<sup>19</sup>:

•	nursing homes and protected living;	CASS
•	short term admission;	CASS
•	day / night relief;	CASS
•	crisis admission;	CASS
•	24 hour assistance services and acute rooms ('zotels');	CASS
•	home care / house help;	CASS
•	Preventive home visits and activating services;	CASS
•	Transportation;	CASS
•	Day centres (recreational);	CASS
•	Loan of equipment and aids;	CASS
•	Meals on wheels;	CASS
•	Home adjustments;	CASS
•	Personal alarm systems.	CASS

The supplies are mostly in kind, only recently financial compensation is introduced. Informal carers (personal assistance) are part of the care in-kind as well as the personally bound budget. They receive only 80% of the payments of a professional carer. The municipality does a yearly check on the informal carer, to see if he or she is capable for the job and to make a new contract.

### **Legal Framework and Funding**

The basic law concerning long-term care and social service is called the Consolidation Act on Social Service (CASS). According to this law, all decisions concerning help to those entitled to social service have to be taken as an individual and concrete decision by the local authorities. So, this means than that the local authorities are responsible. The principal statutes governing the social policy area are, in addition to the Consolidation Act on Social Services, the Social Pensions Act (SPA) and the Act on the Rule of Law and Administration in the Social Field (ARLASF). In 2003 a new law called 'greater choice of provider' (2003) was passed, which results in the fact that private providers as well as public providers from the local authority can offer long-term care and social support. There are also acts on the housing and care package.

Local authorities finance costs through local taxes (70 up to 80%), through block grants from the government and possibly equalisation amounts received from other local authorities. Denmark has one of the highest income taxes in the world. Some of the revenues are used to pay for social services and benefits.

<sup>&</sup>lt;sup>19</sup> General practitioners as participants in long-term care are not considered as they usually are categorized in the cure.

National legislation sets down basic principles regarding the rights of the individual patient. Privacy legislation is very tight in Denmark, the negative effect of this is that patients sometimes die on the street because no one is able to help them. Psychiatric patients can get ad missed with force.

#### **Actors**

Four actors play a role: the central government, the regional governments, local governments and the private providers.

## Policy Making Responsibility

The national government is responsible for health care finance and implementation of guidelines. Regional authorities are responsible for the administration of funds, the selection of providers and the reimbursement systems at a regional level. Together with the Ministry of Employment and the Ministry of Interior and Health, the Ministry of Social Affairs is, mainly responsible for the social welfare tasks in Denmark. The Ministries have a responsibility to make sure that the law is followed by the local authorities. Central government lays down the general legislative framework for the provision of services for older people but the local authorities decide on and are responsible for the range and organisation of services provided. The local authorities have the overall responsibility to the concrete formulation of elderly policy, to make sure that the needed deliverance is provided, in housing, elderly care and social service/welfare.

#### **Operational Responsibility**

The system of delivering care services is decentralised. Regional (16 counties) and local authorities (275 municipalities) administer health and social policy respectively. It is the local authorities who pay for the services, set the standards of help and decide how much help different people are entitled to. local authorities can provide the care themselves or since 2002, hire a private provider. In the last case the local authorities keeps the responsibility for arranging and paying for home nursing (Bertelsmann Foundation, 2003). The great majority of welfare tasks are carried out by public employees, and not, for example, by private service companies, voluntary social organisations or the family. A small amount of care is provided by private providers. The provider (the local authorities or the private provider) is responsible for delivering the help decided upon by the local authority.

## 3.3.2 Danish Policy Instrument Mix arranged on Long-term Care and Social Support Topics

#### **Quality Standards**

There are no national formulated quality standards concerning the quality of services provided in long-term care and social support. Danish legislation requires that local authorities prepare quality standards, including a description of the service level decided by the local authority. These quality standards must be adopted by the local providers, which at least once a year must follow up on the quality and management of the services provided. In the same period the Ministry of Social Affairs developed a model for better practices, follow up – procedures and embedding of quality standards in local providers and to ensure widespread use of the model (Bertelsmann Foundation, 2002). Local

authority quality standards can ensure coherence between political decisions concerning service levels and the resources set aside for them, decisions concerning help and assistance, fundamental values governing the performance of services (including value-based management) and the help and assistance provided to individual citizens. These quality standards must describe the services available to citizens to be provided at a local level. Descriptions of the nature, scope and performance of help and assistance must be concise, and must include quality objectives (operational objectives), which the local authority can subsequently use to evaluate performance and results. This includes performance of services meeting the quality standards set by the local authority.

#### **Quality Assessment**

A voluntary, private certification scheme called Certification of Quality Management and Development of Eldercare has been subsidized by central government to monitor and develop the quality of services provided to older people through recognition. There are no statutory certification schemes in operation in Denmark. The private certification scheme covers all services offered in the field of eldercare. To obtain certification, providers of eldercare must meet certain standards in three key areas: management, objectives and services, and process and resource management. Having obtained certification, service providers are entitled to describe their services as 'quality-certified eldercare services' and to use a certification logo or to carry a quality mark.

A monitoring programme started in 2002 by the local authorities to restore trust of Danish senior citizens in the care institutions. The local authorities formulated a joint plan regarding the quality of care for older people in residential homes and other types of elderly housing.

#### Inspection

No information was available on the presence of long-term care or social support inspection or monitoring.

## **Professionals**

There is no legislation concerning long-term care professionals, registration or disciplinary boards. Employees effecting personal and practical care and assistance are to a great extent recruited from a basic social and health education and training programmes. This basic social and healthcare helper education and training programme runs for 14 months, while the second part runs for 20 months and leads to a diploma of social and healthcare-assistant. Various programmes of continuing education and training are available on an ongoing basis for people working in the social sector (e.g. social and healthcare staff, nurses, managers).

#### Innovation

The central government in Denmark has a role in innovation concerning starting innovative programmes, subsidizing those programmes and persuading the local government to adhere to it. The local government's most important task is to implement those innovations.

### **Transparency**

In 2002 the central government set up a database containing information about price and quality of long-term care. Local authorities must formulate and publish quality and price requirements applying both to public and private service providers. Local authorities have to be able to isolate the costs of home help services and make them transparent.

### Complaints

Citizens can complain about house help at the municipal council based on generic administrative legislation. There is no formal right of complaint.

#### **Residents' Committees and Participation**

No information was available on the presence of residents' committees.

On a local level citizens have influence on long-term care and social support policy arranged in local municipal councils for residents.

## **Choice Supporting Information**

As part of a joint plan regarding the quality of care the municipalities set up councils for residents and their relatives in 2002. A designated representative of the municipality should examine each situation annually. Those councils do not have a legal status.

With a view to supporting and promoting the free choice of providers of personal and practical help and assistance, the Danish Ministry of Social Affairs has set up a central database with the data needed to ensure a genuine free choice for providers both for citizens and local authorities and to create a transparent market for service providers. The database must include all price and quality requirements formulated by local authorities for home help as well as the names of all service providers who have been approved to supply home help (Ministry of the Interior and Health/EPC2002). This information only concerns social service / home help, not nursing homes.

#### **Cost Control**

In Denmark several methods are used to control costs and at the same time still guarantee a certain level of accessibility of long-term care delivery. For instance, there are;

- Fixed salaries and budget regulation at a regional level;
- Price negotiation with providers for the care delivery;
- Compensation limitations;
- User fees:
- Needs assessment;
- Support for informal carers.

#### **Compensation Limitations**

The local and regional authorities determine the content and extent of the assistance offered (the service level) on the basis of local conditions. They provide resources for the services in compliance with general political objectives concerning service levels.

#### Price Settlement and Budget-regulation

Budgets are established by the local and regional political processes. Prices are set both locally and regional through agreements with private providers, otherwise (when public delivery) there are management contracts.

#### User Fees

Danish legislation only allows local authorities to demand payment for permanent practical assistance and personal care in people's homes to a very limited extent. Local authorities are not allowed to demand payment of expenses relating to staff providing personal care and practical assistance, but they are allowed to charge for products and materials used. There is also a limit on compensation for home adaptations, from this turning point on people are sent to government owned adapted housing. All residents of institutions have to manage their own income and pay rent, electricity, health and for services such as transportation, meals, hairdressing, shaving, recreational facilities, aids. A part of their old age pension is withheld if they live in a facility for older people. The local authority is responsible for setting the rents and service charges.

#### Needs Assessment

On January 1 2003 a distinction in the need assessment between long-term care and social service is implemented, which should give citizens more clearness about who is responsible for the need assessment. Needs assessment is performed by a health visitor/social worker, who is at the same time the client's case manager. Every person in need of support has a case manager in the municipality, who is the individual counsellor of the person applying for support. The case manager coordinates the efforts and cancels care provision when the elderly is hospitalised, on vacation or visiting relatives. For nursing care the GP and/or home help services can perform the needs assessment. Provision of care does not take into account the help that is provided by adult children or other family members living outside the household. The entitlement or eligibility criteria applied, and the number and type of social services are all dictated by the budget and political preferences of the local authorities. Some local authorities may be evading the law by withholding home help for domestic care.

## **Informal Care Support**

Assistance given by family members or relatives is considered additional input rather than a substitution to the assistance provided by public services. Although there continues to be a culture of additional support provided by family members, in particular by children of older people, family care is rarely a substitute for public care. Relief and respite care is provided to spouses or other close

relatives who look after a person with impaired physical or mental capacity. Relief is provided in the person's home, while respite care is provided outside the home, for example in the form of accommodation at a nursing home or care facility during the day or night, or both. Caregivers of terminally ill patients (palliative care) are entitled to social assistance to compensate for lost earnings. Care givers receive a cash benefit equal to 1.5 times the sickness cash benefit they would have received in case of being sick themselves. Cash benefit can never exceed an individual's former income.

#### 3.4 Sweden

## 3.4.1 General Information on the Swedish Long-term Care and Social Support System

#### Definition

Sweden has no formal definition of long-term care. The definition of long-term care is based on a need for care. The entitlement to long-term care is not based on a minimum level of care needed nor on a minimum duration.

#### Objective

The basic principle of the care for elderly is to guarantee economic certainty, good housing and aid and care to need. The client has freedom of choice and influence on the standard of living. The rights are universal and everyone is entitled to a good well-being independent of age, gender, ethnicity, place of residence and purchasing power.

### **Target Groups**

- The following target groups can be distinguished:
- Elderly;
- Mentally disabled;
- Physical disabled;
- Sensorially disabled;
- · Chronically ill;
- Long-term care demanding psychiatric patients.

There is a distinction between people younger than 65 and over 65 with handicaps. If you are younger than 65 social support entitlement is no problem to make sure you will participate in society, but when you are older than 65 people have longer entitlement on social support based on their handicap, except when you already were entitled to social support.

## **Care Arrangements**

Concrete care supply includes:

nursing and care (exclusively regionally use);

HSL/SOL

• day and night relief; SOL

short term admission;

SOL respite care; Day centres: LSS/HSL Home care and house help; SOL/LSS meals: SOL • home adaptations<sup>20</sup>; LSS transportation; SOL/LSS LSS alarm devices; aids. LSS

The supplies are mostly in kind, only recently financial compensation is introduced. By law of January 1<sup>st</sup>, 1994 is the right to remuneration for assistance/caregivers formalized. This economic support can be used to hire one or more private or public assistants for certain care tasks through the municipalities.

## **Legal Framework and Funding**

The following laws are relevant:

- Social Service Act (SOL);
- Health and Medical Support law (HSL);
- Law for Support and Service to People with Certain Functional Shortcomings (LSS);
- Municipal Liability Act for Certain Health Care.

The Social Service Act contains regulations regarding specific right to financial and social assistance, and the municipal authority's responsibilities towards residents or the municipality. The target groups as earlier mentioned fall under several laws. For the elderly the first two laws (SOL and HSL) are the most important. The disabled fall under the SOL and LSS. The last mentioned law (liability) regulates the financing of the long-term care. The Social Service Act is financed by income tax. The largest part is financed by local tax turnovers (84%-85%), a part is financed with national taxes (10%) and a small part (4%-5%) is financed with personal contributions. The LLS entitlements are financed through taxes.

## **Actors**

Three actors play a role: the central government, the regional governments, local governments.

### Policy Making Responsibility

At a central level legislation and economic targets are set. The regions and municipalities have a high degree of autonomy. Within the frameworks they can levy taxes and indicate priorities. The municipal level (there are 290 municipalities) is obliged by law to provide sufficient social and medical services and living facilities for the elderly and the disabled. The local government has a very high degree of autonomy. They have the right to levy taxes. The county councils and the municipalities may, within

 $<sup>^{\</sup>rm 20}$  Home adaptation are done by the municipalities own technical service.

the limits prescribed by the existing legislation, decide the degree of priority they will give to the elderly over other groups.

## **Operational Responsibility**

At a regional level (there are 21 regions) lies the responsibility for the offer of supplies of health care and medical services. The nursing component of home care also falls under the responsibility of the regions. In 90% of the cases the municipalities provide the care themselves. In almost 10% of the cases local governments work on a contractual basis with private providers. The local government is responsible for the financial and qualitative conditions of a contract.

3.4.2 Swedish Policy Instrument Mix arranged on Long-term Care and Social Support Topics

#### **Quality Standards**

In Sweden there are no national standards regarding quality and accessibility of professional long-term care. In the SOL (1982), a new paragraph was enacted in 1998 requiring that "social services should have high quality and the authorities are requested to have manpower to ensure that". The Social Service Act is enabling legislation. It is up to the municipality to decide on need assessment and standard of services provided within the context of the law. In the 90's the National Board started to issue guidelines considering care for chronically ill. Those guidelines provide a basis for regional and local care programmes.

#### **Quality Assessment**

The local government's agrees on a quality assurance programme with the long-term care and social support providers.

## Inspection

On the basis of current laws, monitoring and supervision of services is carried out by two different authorities: services based on the SOL (i.e. most of the services provided by the municipality) are monitored by the County Administrative Boards. Long-term care is monitored by the Nation's Board of Health and Welfare.

#### **Professionals**

There are national education criteria for nurses. There is a Nation's Board of Heath and Welfare which handles the registration of professionals. There is a National Medical Disciplinary Board for nursing.

#### Innovation

Programmatic innovation, for instance 'new models for supporting carers', is financed by the central government.

### **Transparency**

There are local monitors on price and quality.

#### **Complaints**

If a client is dissatisfied with the care managers' decision concerning requested services, the case can be appealed against in the administrative court. There is no specified legal right of complaint.

## **Residents' Committees and Participation**

No information was available on the presence of residents' committees and local participation of (potential) care and social support users.

#### **Choice Supporting Information**

No information was available on the policy objectives concerning choice supporting information.

#### **Cost Control**

In Sweden several methods are used to control costs and at the same time still guarantee a certain level of accessibility of long-term care delivery. For instance, there are;

- Compensation limitations;
- Price negotiation with providers for the care delivery;
- Budget regulation at a regional and local level;
- Labour cost management (e.g. reduce staff density or hold back salary increases or employ care personnel by the hour);
- User fees;
- Needs assessment;
- Support for informal carers.

#### **Compensation Limitations**

Many municipalities have also cut down on the level of services and/or dismantled certain programs. Eligibility for the services is changed in order to target the services to the most frail and needy.

### Price Settlement and Budget-regulation

In Sweden the traditional strategy for budget-regulation was an increase of taxes in order to finance services. However, citizens didn't believe anymore that this would be the solution in the long run. Therefore the government forced a tax-ban in the mid nineties. The municipalities' most common strategy now is to. A greater share of the costs for services and care is shifted over to the individual user and the fees for services are increased. Prices are set both locally and regional through agreements with private providers, otherwise (when public delivery) there are management contracts. Financing is open-ended.

#### **User Fees**

The recipient pays a fraction of the actual costs for health care and social service. Charges vary among the municipalities. The user's fees have been increased, but are limited. No one has to pay more than 2200 SEK (approximately €239) per year for health care regardless of the type and amount of care received. The fees for home help are related to how much help is needed and to client's income. In 2002, a central law was enacted introducing a 'floor and ceiling system', regulating the maximum level of charges as well as the guaranteed amount of disposable income (the floor) to be left, after the cost for housing, services and care are paid.

#### Needs Assessment

Each municipality decides on their own eligibility criteria. Elderly care provision is based on a single entry system; the person in need for help turns to the municipality where he or she lives, to claim help. Needs determination takes place through a process of needs assessment, carried out by a municipal aid executive/social worker. An individual could claim services but has no automatic right or entitlement to services. The aid executive/social worker is both responsible for the assessment and the organisation of the provision of help (Ministry of Health and Social Affairs/EPC, 2002). Officially, informal care does not play a role in the needs assessment, in reality there is the expectation that informal carers deliver support services for their relatives. Home adaptation needs assessment is done by an occupational therapist.

#### **Informal Care Support**

There is no legal obligation for families to provide care. There are three types of support: respite and relief services, support and educational groups for carers and economic support for caring. In the revised Social Service Act (1998) parliament has introduced a new paragraph, urging the municipalities 'to support families when caring for elderly, disabled and long-term sick persons'. Caregivers also have the right to unpaid work leave. In the municipalities there are often informal care support groups as well as an informal care consulate. There is a care allowance which can be used by informal carers to hire carers in case of respite care. There is no regulation on care-allowance, local authorities decide on these.

## 3.5 Germany

3.5.1 General Information on the German Long-term Care and Social Support System

#### **Definition**

In Germany long-term care has been clearly delimited and defined: a person is applicable if he/she has a substantial need for a minimum of 10.5 hours a week, based on B-ADL<sup>21</sup> and I-ADL which will last for at least 6 months (according to expectations).

<sup>&</sup>lt;sup>21</sup> On the basis of B-ADL or Katz-scale one assesses the basic activities of the patient. One asks to what extent he can wash, dress, move his/herself etc. In the I-ADL or considering the 9 points of Lawton more complicated activities are assessed such as managing its own finances and taking the medication.

### Objective

Clients have the freedom to choose their own care provider. By law (Pflegeversicherungsgesetz) extramural care is preferred above intramural care.

#### **Target Groups**

The following target groups can be distinguished:

- Elderly;
- Mentally disabled;
- Physically disabled;
- Sensorially disabled;
- Chronically ill.

There is a discussion concerning psychiatric care. The reason for this is that care need is based on ADL, which does not measure the special circumstances of mental illnesses.

## **Care Arrangements**

Concrete care supply includes:

•	Nursing homes and care homes;	PVGS
•	Protected living;	PVGS
•	Short term admission;	PVGS
•	home care and house help;	DSCA
•	Day centres;	DSCA/PVGS
•	day and night relief;	DSCA/PVGS
•	meals;	DSCA

**DSCA**  alarm devices; **DSCA** prevention.

Supplies can be money (15%) or care in kind (85%). There are no restrictions on what kind of social support of care the money is spent. Complementary services such as housekeeping, meals on wheels, family nursing and those of the so-called open care of the elderly people (cultural and social programmes, meeting places) are eliminated in many regions.

## Legal Framework and Funding

For those people that are eligible for long-term care there is obligatory social long-term care insurance: the Pflegeversicherunggesetz (PVGS) (Mörer-Funk, 2002). People that have statutory health insurance - compulsory or voluntary - have automatically statutory long-term care insurance as well. Long-term care insurance is financed through contributions that are scaled according to income. The contribution assessment ceiling that applies to health insurance also applies to long-term health insurance. People that have private health insurance and are entitled to general hospital care, need private long-term care insurance as well. Besides the PVGS there is private long-term care insurance. On 1 January 2002 the Act Supplementing Domiciliary Care Services (DCSA) came into force. This act aims at improving the services offered by the long-term care insurance, in order to strengthen the in-home services for people requiring a considerable amount of care. The DCSA provides a range of service improvements for people in need of care in domiciliary or semi-inpatient settings. If family income is insufficient and informal care is lacking, clients can appeal to the Social Assistance Act (Sozialhilfe, BSHG). Social assistance is means tested. Moreover there are laws which provide guidelines for the supply of care (Mörer-Funk, 2002).

For the compulsory social insurance system the premium is income dependent and is determined by the national government. People pay a premium of 1.7 percent of the gross income for the long-term care. Assistance is financed with tax turnovers.

The rights of the citizens of Germany have been laid down in law, for instance in the Act on Equal Opportunities for Disabled Persons (AEODP).

### Actors

There are several players in the field of long-term care: the states (Länder), the municipality, the funds for long-term care and the private providers.

## Policy Making Responsibility

Central government has no direct responsibility for offering care; that responsibility lies with the states. The 23 Länder are responsible for a productive, economically efficient and adequate infrastructure for ong-term care. No care districts have been defined, the care regions usually correspond to the Länder.

## **Operational Responsibility**

Moreover they are responsible for financing the investments in long-term care. The states pass on the responsibility for long-term care mainly to the insurance companies. The insurance companies board the services by means of contracts to the (voluntary) non-profit and private sectors. The public sector plays a very small role in the offer of long-term care in Germany. The private and non-profit sectors, on the other hand, are relatively strongly present.

3.5.2 German Policy Instrument Mix arranged on Long-term Care and Social Support Topics

#### **Quality Standards**

The Care Quality Bill is a project of the Federal German government, and was formed in 1998 and has been supplemented ever since. It responds to two developments which are the result of the long-term care insurance. The attitude of the care users has changed, they demand the best available care of the best possible standards. Developing those standards, the Federal Association of Care Providers and the long-term care insurance funds made nationwide quality agreements. An initial Bill to Improve the Care of People Suffering form Dementia is under consideration.

### **Quality Assessment**

Care providers and long-term care insurance funds are responsible for the quality of care based on the Care Quality Bill. A quality agreement, laid down in a contract, is one of the instruments. New regulation makes it possible for long-term care insurance funds to select providers based on qualitative factors and to follow a pro-active comparative information policy.

## Inspection

Public inspectors and (medical services of) long-term care insurance funds are responsible for a quality inspection but only if there is a reasonable cause for suspicion or inadequate or harmful care. Public inspectors are part of the Federal Ministry of Health.

#### **Professionals**

In 1999 parliament passed a law on Professionals engaged in the Care of the Elderly, supplemented in 2002 by the Law to Reform Nursing Profession. This legislation organizes national quality standards for professionals. In the nursing professions there are basic qualifications but there are also professionals with no or less qualification. There are no special criteria for professionals working in long-term care. 69% of nursing personnel of outpatient care has completed training specialist, such as geriatric assessment, QA, planning, 16% has had no training. Training and accessibility are regulated differently from region to region. Largely unified curricula are differently organized per region. There is central enabling legislation for the organization of the registration of professionals.

#### Innovation

There is programmatic regulation for improving the coordination of care. But it still has not taken on a very concrete form. There is a budget of  $\in$  5 million euro a year which can be used for this. It is especially meant for personal budgets and to develop new forms of housing. There is regional legislation to regulate coordination of care more effectively. The implementation of the programme as well as the legislation gives problems. The problems concern binding agreements in particular. At the same time, there are the same problems with the allocation of costs. In Germany long-term care has no academic or professional status, and therefore there are no government sponsored innovation programmes.

#### **Transparency**

No information was available on the policy objectives concerning transparency in Germany.

## Complaints

No information was available on complaints management in Germany.

## **Residents' Committees and Participation**

No information was available on the presence of residents' committees and local participation of (potential) care and social support users.

## **Choice Supporting Information**

For the coordination of the still largely unconnected services for handicapped and elderly people, combined service units should be set up in all districts according to the Code of Social Law. These centres deliver comprehensive consultation. There are surveys for clients' satisfaction measurement.

#### **Cost Control**

In Germany several methods are used to control costs and at the same time still guarantee a certain level of accessibility of long-term care and social support delivery:

- Price negotiation with providers for the care delivery;
- Compensation limitations;
- · User fees;
- Needs assessment;
- Support for informal carers.

#### **Compensation Limitations**

For different categories of care there are legally established maximum compensations for monetary benefits and benefits in kind (per capita lump sums based on the level of needs and the selected form of service to be provided), which generally offer only partial coverage for each care and service type. Another manner to limit the annual cost development is not indexing these standard compensations.

#### Price Settlement and Budget-regulation

Private providers compete with each other for contracts. Particularly there is a competition on the basis of both quality and price. There is no monitoring of the pricing. The government is a negotiation partner in determining the prices and can intervene with its veto. Prices should reflect market prices, used by some institutions to gain profit. There are guidelines for highest increase rates and profitability checks. There are almost no dangers for the insurers because benefits are limited to a maximum and there is an afterwards settlement of accounts concerning volume (the number of clients) in case shortages arise.

Assistance is a clear open-ended financing. In the negotiations with care providers social assistance is the party which has to enforce low prices. Assistance pays care costs which are not insured and cannot be paid for by the client. In the negotiations with the care providers they have thus a veto (Socialgesetzbuch XI, first amendment).

## **User Fees**

Personal contribution is depending on the degree of care dependency and the chosen institutional arrangement. For every arrangement there is a maximum equivalent of money per person receivable. Customers that go beyond this level, have to pay the exceeding amount themselves. This can be seen as a personal contribution. Customers with less than 10.5 hours of needed care, have to pay for care entirely themselves. Costs for board and lodging remain to be paid by the residents (or by the social

welfare system) as well as costs for further social or health related services and aids that are not covered by long-term care insurance, e.g. housekeeping.

#### Needs Assessment

People are eligible for care when they require frequent or substantial help with normal day-to-day activities on a long-term basis (six months or longer) in four different areas (personal hygiene, eating, mobility and housekeeping). Then an assessment will be made to decide which level of care a person needs. The indication interview is performed by the insurer. Formal appraisal is made by a doctor and a nurse. The assessors report to the local insurance fund for long-term care, which pays the care services according to the needs assessment. Needs assessment is introduced to avoid excessive claims, but also to control quality.

## Informal care support

Long-term care is considered the prime responsibility of family and friends. 70% of those in need of long-term care receive informal care by family and friends. There are advantages for informal care providers. When delivering informal care, family members can qualify for pension insurance, depending on the extent and duration of the support. There are also favourable conditions for accident insurance. Moreover lectures and seminars for informal care providers are organised by private organizations. Sometimes, however, these professional programmes that are meant to provide relief, in reality imply additional efforts for family carers. Relief services are maximized at 4 weeks a year.

## 3.6 England

### 3.6.1 General Information on the English Long-term Care and Social Support System

#### Definition

In England there is no legal formal definition of long-term care. The long-term care definition is based on a need for care. Care need is dependent on the functioning of a person summarized in the need for support in daily activities (ADL or I-ADL). The term especially targets on the type of aid that is needed; mostly domestic tasks, support in cooking, personal care or assistance, washing, dressing and support. The entitlement to long-term care is not based on a minimum level of care needed nor a minimum duration.

## Objective

The long-term care system is based on the principle that meeting care needs of older people is primarily a responsibility of the individual and the family rather than a responsibility of the state.

#### **Target Groups**

The following target groups can be distinguished:

- Elderly:
- People with physical problems or learning disabilities;

- · Sensorially disabled.
- People with mental illnesses
- · Chronically ill;

## **Care Arrangements**

Concrete care supply includes:

nursing homes (psychiatric patients);
 care homes;
 protected living;
 short term admission;

HSCA
NHS/HSCA

Day and night relief;
Home care and house help;
Social centres elderly;
transportation services;
meals;
HSCA

aids;
 NHS/HSCA

home adjustments;prevention;HSCA

The supplies can be money or care in kind. Only for adult physically disabled and elderly people sometimes money is offered (attendance allowance and disabled living allowance).

## **Legal Framework and Funding**

In England an all inclusive law on long-term care is lacking. The current system has evolved over the years to what it is now. At this point long-term care is based on several statutes which govern the National Health Service (NHS) and the Community Care Act (CCA). The NHS statutes consist of the Health Act (1999), of the Mental Health Act (1983) and of The Carers and Disabled Children's Bill among others (Department of Health, 2004). The Community Care Act has reformed long-term care by transferring the responsibility of long-term care from institutional care towards community care i.e. local authorities and the independent sector. This has led to a blurred distinction between the NHS and Social Service. The NHS is responsible for health care, geriatric hospital units and limited nursing care at a local level. Local Authorities are responsible for different social services such as institutional care in nursing homes or residential homes adult day care centres, assistant devices domiciliary services (nursing care, care and assistance). In 2001 the Health and Social Care Act (HSCA) was enacted. The most important changes were free nursing care, better services on long-term care and to make the current system more transparent (Larsen, 2004).

Long-term care is financed from general taxes and by user fees by the customers. The NHS is financed from the central general tax and a small part originates from National Insurance. The care provided by the local government is financed with central and local taxes and personal contributions<sup>22</sup>.

A Patients' Charter outlines people's rights with respect to the NHS and sets standards for treatment. It was reviewed in 2000. There is also a national Disability Discrimination Act (1995) which strives for equality.

#### **Actors**

Four actors play a role: the central government, the National Health Service, the local governments and the private providers.

#### Policy Making Responsibility

The central government of England is responsible for long-term care<sup>23</sup>, but does not play a large role in the organization of care. The state has delegated the prime responsibility for service planning and resource allocation to two organizations, the National Health Service and Local Authority Personal Social Service Departments, the local authorities. However, the central government keeps supervision of the situation and intervenes if she considers it necessary. The intention is that patients with mainly a medical need fall under the NHS and care and well-being is the responsibility of local authorities.

#### **Operational Responsibility**

Local governments have a large autonomy. The contribution local governments receive from the central government can be spent to their own insights. Local government stipulate the rules for the different entitlements, but the central government determines the working method. The criteria on which someone can receive care differ from municipality by municipality. The NHS is mainly responsible for the medical side of care, including nursing care. Psychiatric and elderly care (nursing) are part of the NHS. Parts of the long-term care fall under the responsibility of the NHS. However, it occurs that there sometimes arises discussion in the grey area between NHS and local governments. Sometimes this means that patients are sent from pillar to post. Most social support is provided by private organizations under contract to local authorities or freelancing themselves. Most care homes are now private and a lot of in-house services are also contracted out.

## 3.6.2 English Policy Instrument Mix arranged on Long-term Care and Social Support Topics

#### **Quality Standards**

There are national and local standards regarding quality and accessibility of professional long-term care. The national services framework for older people is a recent document setting out national

<sup>&</sup>lt;sup>22</sup> There is also still a possibility for individuals to take an additional insurance for long-term care, but is hardly used (only 35,000 users)

<sup>&</sup>lt;sup>23</sup> Scotland, Wales and Northern Ireland carry their own responsibility, which means that policy and organisation can differ among the different countries of the United Kingdom. In this research paper we will focus on England.

standards for care laid down in the NHS. On a local level quality standards are defined within the Social Service Act.

#### **Quality Assessment**

There is no quality assessment in England. Professionals were not interested in quality assessment and quality management systems, while they already had their own elaborate professional procedures on quality (see 'professionals').

## Inspection

The National Care Standards Commission is responsible for regulating and monitoring the quality of long-term care services in England. It was set up in 2002 as an independent national watchdog. It is responsible for the registration and inspection of care homes and domiciliary homes. The National Care Standards Commission and the Social Service Inspectorate were merged into an independent Commission for Social Care Inspection in April 2004. A number of new bodies are introduced to assist in monitoring the NHS at national level: for instance the National Patient Safety Agency and the Commissions for Health Care Audit. Those committees concern only the NHS, not social services. In England inspectors quality reports are usually available to the public.

#### **Professionals**

In England there is a long tradition of acknowledged caring professionals and quasi-professionals relevant to long-term care. Recently, lower status care workers have had to acquire vocational qualifications in care, with precise levels and requirements varying by client group and form of care. Negotiation on these vocational requirements is done by the National Training Organisation for Social Care, the General Social Care Council (GSCC) and the National Care Standards Commission (NCSC). The GSCC was established in October 2001 under the Care Standards Act 2000, as the guardian of standards for the social care workforce in England. Its overall role is to increase the protection of service users, their carers and the general public by regulating the social care workforce and by ensuring that work standards within the social care sector are of the highest quality. It also acts as a champion for social care to help give it the recognition it deserves. The Social Care Register<sup>24</sup> was launched in April 2003 with the aim of registering all social care workers in England similar to that for nurses. To be able to register, workers must have an appropriate qualification, commit to uphold the Code of Practice for Social Care Workers and be physically fit to do their jobs. Codes of Practice for social care workers and employers were launched in September 2002. The codes set out the

<sup>&</sup>lt;sup>24</sup> The GSCC is also responsible for regulating and supporting social work education and training (Ministry of Health/EPC, 2002). The GSCC:

<sup>•</sup> accredits universities that offer the social work qualification;

quality-approves all accredited social work courses at qualifying and post qualifying levels using a standardised set of quality assurance criteria and processes;

administers bursaries to social work students to support them throughout their qualifying studies;

provides guidance to the assessment of practice in the workplace;

conducts reviews and consultation related to social work qualifications. For example the second phase of consultation of the Post Qualification Framework was launched in mid-2004;

provides information about and promotes careers in social care and social work.

standards of practice and conduct guidelines social care workers and their employers should meet (Ministry of Health/EPC, 2002). A disciplinary board is arranged in the 'Professions Supplementary to Medicine Act'.

#### Innovation

There is a strong emphasis on best value. Where new services are created these must be capable of demonstrating their strengths and efficacy against existing models in order to secure ongoing funding. There are covenants for public private partnership proposals. Health authorities and the joint consultative committee's do initiate innovation in partnership by subsidizing them.

#### **Transparency**

Transparency in long-term care and social support is given by performance indicators. But the use of performance indicators is in a starting phase. Every local authority has to publish annual performance tables for all departments including social services. The National Audit Commission supervises the system.

#### **Complaints**

The right to complain is arranged in the local Patients Charters. Complaints which are not settled locally can be sent for independent review. If this does not produce a satisfactory resolution, they can be referred to the Health Service Commissioner (type of Ombudsman) who is independent. Complaints about social services should be addressed at the Local Authorities; they have their own complaints committees (Beasley, 2004). Patient Advice and Liaison Services should help resolve problems before they become a complaint. There are also local authorities' Ombudsmen.

#### **Residents' Committees and Participation**

The Community Health Councils (CHC) gave local people a limited role to play in monitoring their area's health care services. In April 2004 the CHC were replaced by Patients Forums, which operate in every NHS Trust. These can not be seen as residents' committee, but regulate the participation of citizens on the long-term care en social support in their municipality.

## **Choice Supporting Information**

There are local client support organizations and telephone lines. These are most of the times private organizations and sometimes governmental organizations. The local client support organization can be described in the local patient charters.

## **Cost Control**

In England several methods are used to control costs and at the same time still guarantee a certain level of accessibility of long-term care and social support delivery:

- · Compensation limitations;
- Price negotiation with providers for the care delivery;

- User fees;
- Needs assessment;
- Support for informal carers.

### **Compensation Limitations**

The decisions about who gets care and what type of care is provided is taken at the local level, by local authorities and primary care trusts. Differences in the levels of care available in different local authorities have led to complaints about geographical inequalities.

#### Price Settlement and Budget-regulation

The long-term care and social support is operational within a fixed, cash limited budget, which means that resources are supply-determined and not a function of demand. Social support for disabled and informal care support are open-ended. For establishing more efficiency and quality the principle of government by the market was introduced. For those agencies that provided the care, the notion of competition entered the arena, providing an incentive for increasing responsiveness to the needs of service users and attending to cost and quality.

#### **User Fees**

The nursing services and district or community services (NHS) are free of charge to the service user. For domiciliary care services, and adaptations or equipment and aids (social service), the provision is means tested and the recipient may have to contribute to the cost or even pay the full price, depending on income and level of savings. Rehabilitation care is free of charge when provided by a hospital, but if social services are the provider then the client may have a means tested prescription charge.

### **Needs Assessment**

The general practitioner or district nurse assesses the medical needs, and should also recognise whether social needs are becoming an issue and informal carers are no longer able to cope, they refer the older person for an assessment of care needs by social workers. In emergencies people or their carers can bypass the GPs and gain direct access to more specialist services through direct contact with a social service team. When there is a discharge from a hospital, a joint assessment is conducted by a qualified nurse, a care manager, occupational therapists/psychotherapist, the patient himself and very often the immediate family or informal carers. The availability of informal support is taken into account at the needs assessment. There is no standard needs assessment instrument, a 'broad information gathering tool' is used. Every member of the team can make use of it to collect information. Since April 1, 2004 new legislation is implemented for a single assessment procedure for the elderly people. This should give an answer to the problems with the dividing of health and social service.

## **Informal Care Support**

The 1995 Cares (Recognition and Services) Act came into force in 1996. This Act recognizes carers and their special role. The local authorities had to decide how to deal with the (financial) consequences of this Act (Höjgård, 2003). For informal carers who take care of a relative or friend for more than 35 hours a week, the Invalid Care Allowance exists. This benefit is means tested and payable at € 61 a week. It is intended to recompensate the carer for loss of paid employment, but the amount is really quite small (working the same hours even at the minimum wage would generate an income of about € 230 very week).

## 3.7 Summary

In this chapter five European countries and their long-term care and social support organization are described. The description is based on literature, questionnaires and interviews. For some topics we did not succeeded to get complete information.

## 4. A Comparison of five European Countries

### 4.1 Introduction

In the previous chapter, the organization of long-term care and social support for the five countries in our survey were described. Based on these descriptions the comparative analysis framework as defined in the second chapter can now be filled. The next step in our analysis is to see which conclusions can be derived from the comparison, as shown in the concluding table 3.1, with respect to the development of the Dutch Social Support Act. To be able to do this, we need to study the specific topics placed on the vertical axis of the comparative analysis framework in more depth. Within this analysis, there are some specific points of comparison which are especially important when looking at the policy topics under investigation. It is important to describe the following when comparing a specific aspect:

- which (type of) policy instruments are used to obtain the policy objective;
- whether it is the local, regional or central government which uses these policy instruments (mixes);
- whether there is a difference between the way of achieving the policy objective mentioned, considering the fact that there is a difference between care and social support arrangements.

These three aspects will therefore be taken into account in our comparison. To facilitate the comparison, every topic will be lifted out of the comparative analysis framework into short tables, which will focus on one or a few related topics at the same time. The intent and content of each table will subsequently be explained. Regarding each table of comparison, the most striking differences between the different countries will be explained. On the basis of these analyses, conclusions and suggestions for the development and/or implementation of the Social Support Act will be given. These conclusions, however, will only be indicative and will possibly need further investigation. Where needed and/or possible, the results of the analysis will be connected to draw more profound conclusions. The following sections will show the comparisons. First, in section 4.2, a comparison between general aspects will be made. In section three, the different topics of investigations will be considered. Section four will summarize our findings.

## 4.2 General Features of Long-term Care / Social Support Systems Compared

## 4.2.1 Definition and Target Group

Table 4.1 compares the various countries on a formal definition of long-term care and social. As was described in the second chapter, such a definition is important because it relates to the scope (e.g. target group, eligibility criteria of the topic of investigation). The table shows whether there is an unambiguous definition of those who are eligible for long-term care and social support, and if so, how it has been determined. If there is no univocal definition, then we describe how those who are eligible for long-term care and social support are defined in practice.

Table 4.1; Definition of Long-term Care and Social Support and Target Groups

Country	Definition of long- term care and social support	Criteria for determination of long- term care and social support	Target group
Netherlands	No	Determination of needed care by needs assessment	Elderly, mentally disabled, physical disabled, sensorially disabled, psychiatric patients, people with chronic illnesses in need of care
Denmark	No	Determination of required care by case manager	Elderly, mentally disabled, physically disabled, sensorially disabled, psychiatric patients
Sweden	No	Determination of requiored care by a care manager	Elderly, mentally disabled, physically disabled, sensorially disabled and psychiatric patients with long-term care needs, people with chronic illnesses.
Germany	Yes	Expected term of required care for a minimum of 6 months and at least a minimum of 10.5 hours support required every week. Needs assessment is executed by insurance companies	Elderly, mentally disabled, physically disabled, sensorially disabled. Permanent discussion on psychiatric patients.
England	No	Determination of required care by needs assessment on the level of ADL or I-ADL.	Elderly, persons with physical or learning disabilities and mental illnesses

#### Definition

Only in Germany, there is a legal delineation and a definition of long-term care and of those who are eligible for long-term care and social support. In all other countries, eligibility is set by needs assessments (in section 4.3 needs assessment will be further discussed). This fact makes the delineation of what can be considered to be within the definition of long-term care and social support hard to make. Especially, as all countries have a section on an enforceable 'right' to long-term care in their legislation, whereas it is not described to whom this rule applies. On the other hand, this seems to make it easier to change the scope of eligibility, because nowadays it is largely invisible who exactly is eligible or not.

For the development and implementation of the Dutch Social Support Act, this 'unclear' definition makes it hard to draw any conclusions on the delineation that the Netherlands should choose for their definition of long-term care and social support in the future. On the contrary, the comparison reflects the departure points in the following comparisons.

### **Target Group**

Regarding the target group, it is remarkable that psychiatric patients are not treated in a similar way in all countries. Some countries largely categorize psychiatric patients within the curative medicine. This is the fact in England and partially in Sweden and Germany. In the latter two countries in particular, short-term psychiatric care is considered a curative medicine. It is also typical that the chronically ill do not in all countries explicitly belong to the target group of long-term care and social support. Probably this group is also seen as part of the curative sector, or otherwise this group will be categorized within the group with physical disabilities.

This comparison will not give us suggestions for the development or implementation of the Social Support Act. Nevertheless, the fact that in Sweden and Germany psychiatric care is largely placed in the curative sphere is interesting, considering the fact that the Dutch government wants to transfer the

extramural and intramural short-term (shorter than a year) AWBZ-care into the Health Insurance Act (Ziekenfondswet, ZFW).

## 4.2.2 Objective

Because all countries basically refer to the same basic values, as was also assumed in the first and second chapter (section 2.3), it was not interesting to put this topic in a comparative table. It is, however, obvious that all countries implement these basic values in their own ways. Some countries focus on care on an extramural basis (Germany and the Netherlands), some focus on free choice (Sweden), on integrated care (Denmark), on people's own responsibility (Denmark, England and the Netherlands), some on accessibility and quality (Sweden) and so on. At this moment, all five countries also largely focus on affordability; this leads to the fact that packages were reduced over the previous years and accessibility decreased. In this light, it is logical that in the Netherlands the current system is being debated.

## 4.2.3 Arrangements of Long-term Care and Social Support

Table 4.2 compares a selection of arrangements that are offered within the definition of long-term care and social support in the different countries. A short-list is shown, as there are far more arrangements that can be delivered within the definition of long-term care and social support. These are the most important and distinctive. For every type of arrangement, the law aimed at that particular arrangement is given. Sometimes more than one law applies.

Looking at table 4.2, we can conclude that the facilities that are part of the long-term care and social support package are relatively widely ranging in Sweden and the Netherlands, compared to the other countries. The Netherlands and Sweden deliver similar packages. As can be derived from the table as well is the fact that when care is arranged on a local level (for example WW, SOL, DSCA, HSCA) the supply of facilities, such as meals on wheels, transportation, home help, handyman, is largely dependent on the local authority or the region someone lives in. In the table, these facilities were often still marked even though these are no longer supplied by several local authorities. Considering the differences in packages delivered, it seems that in the Netherlands a broader package is delivered than elsewhere, which could suggest that we should reconsider our package in these less prosperous times. Analysing the table, a word of caution should be made; the table shows if something is available, it does not show for whom (eligibility criteria) or to what extent (with or without user fee, a maximum stay, etc.) it is available. The table gives no lead for the determination of a kind of minimal package to be delivered.

It is also remarkable that there are a lot of question marks concerning the facilities for the disabled and psychiatric patients. This is due to the fact that very little has been published on these groups. Presumably this is caused by the relatively small size of the 'defined' target group compared to the elderly. Therefore it is not easy to draw conclusions from the table. This is especially regrettable because the proposed change has a large impact on these groups; the disabled usually have no

Table 4.2; Long-term Care and Social Support Arrangement by Legal Source

Long-term care and social support services for elderly, disabled and psychiatric patients	Netherlands	Denmark	Sweden	Germany	England
Permanent living					
Nursing homes	+ (AWBZ)	+ (CASS)	+ (HSL)	+ (PVGS)	+ (HSCA)
Nursing homes psychiatric	- '	-	- '	- '	+ (HSCA)
Institutions for the disabled	+ (AWBZ)	+ (CASS)	+ (LSS)	+ (PVGS)	+ (HSCA)
Institutions for psychiatric patients	+ (ABWZ)	+ (CASS)	+/- (p. HSL)	?	?
Care homes	+ (AWBZ)	- ` ′	+ (SOL)	+ (PVGS)	+ (HSCA)
Protected living & adapted housing	+ (AWBZ)	+ (CASS)	+ (SOL)	+ (PVGS)	+ (HSCA)
Short term living (selection)					
Rehabilitation	+ (p. AWBZ)	-	-	+ (PVGS)	-
Short term nursing home admission	+ (AWBZ)	-	+ (HSL)	- ` ′	+ (NHS)*
Short term care home admission	+ (AWBZ)	+ (CASS)	- ` ′	+ (PVGS)	+ (HSCA)
Crisis admission disabled	+ (AWBZ)	+ (CASS)	+ (LSS)	?	+ (HSCA)
Crisis admission psychiatric	+ (AWBZ)	+ (CASS)	+/- (p. HSL)	?	?
Day relief	+ (AWBZ)	+ (CASS)	+ (SOL)	+ (DSCA)	+ (HSCA)
Night relief	+ (AWBZ)	+ (CASS)	+ (SOL)	+ (PVGS)	+ (HSCA)
Social centres Elderly	+ (AWBZ/WW)	-	+ (SOL)	+ (PVGS/DCSA)	+ (HSCA)
Social centres Disabled	+ (AWBZ)	+ (CASS)	+ (LSS)	+ (PVGS)	?
Social centres Psychiatric patients	+ (AWBZ)	+ (CASS)	+ (HSL)	?	?
Extramural (selection)					
Nurse assistance	+ (AWBZ)	+ (CASS)	+ (SOL/LSS)	+ (DSCA)	+ (NHS/HSCA)
Home care	+ (AWBZ)	+ (CASS)	+ (SOL/LSS)	+ (DSCA)	+ (HSCA)
House help	+ (AWBZ)	+/- (CASS)	+ (SOL)	+/- (DSCA)	+/- (HSCA)
Handyman	+/- (AWBZ/WW)	-	+ (SOL)	-	+/- (HSCA)
Meals on Wheels	+ (WW)	+ (CASS)	+ (SOL)	+/- (DSCA)	+/- (HSCA)
Transportation	+ (AWBZ/WVG)	+ (CASS)	+ (SOL/LSS)	-	+ (HSCA)
Home adjustments Elderly	+ (WVG)	+ (CASS)	+ (LSS)	-	+ (HSCA)
Home adjustments Disabled	+ (AWBZ/WVG)	+ (CASS)	+ (LSS)	-	+ (HSCA)
Alarm devices/ personal safety alarms	+ (AWBZ/WVG)	+ (CASS)	+ (LSS)	+ (DSCA)	+ (HSCA)
Aids	+ (p. WVG)	+ (CASS)	+ (LSS)	-	+ (NHS/HSCA)
Discount services	-	-	-	-	+
Prevention (i.e. preventive home visits & health checks)	+ (WW)	+ (CASS)	-	+ (DSCA)	+ (HSCA)

Legend: + = part of long-term care and social support arrangements;

For explanation of abbreviations we refer back to the previous chapter

income and are largely dependent on care and social support; and for both groups because local authorities do not have the know-how what to arrange for those groups. The latter can be sustained when looking at the Swedish situation where locally organized psychiatric help gives a lot of trouble. This probably explains the fear of Members of Parliament, local authorities and psychiatric institutions for their transfer to the Social Support Act. Further research to see what exactly went wrong in the Swedish situation can remove this fear and probably give suggestions for the local authorities how to implement psychiatric care (psychosocial shelters and reception centres).

Table 4.2 shows that in most countries a kind of distinction can be made between the activities that are based on a certain law or act. In the Netherlands, there is a distinction between the AWBZ and the WVG /WW, in Sweden there is a distinction between the SOL and the HSL/LSS, in Germany there is a

<sup>+/- =</sup> now and then, sometimes part of long-term care and social support sometimes nothing arranged;

<sup>- =</sup> nothing arranged;

p. = partially, partially part of long-term care and/or social support and partially part of curative medicine;

<sup>? =</sup> no information available;

<sup>\* =</sup> various statutes on which the NHS is governed.

distinction between the PVGS and the DCSA, and in England there is a distinction between the Statutes (e.g. the Mental Health Act) on which the NHS is governed and the HSCA. Only in Denmark, there is only one law which regulates both long-term care and social support. This distinction between the different acts gives a starting point to distinguish between social support and long-term care arrangements. However, this connection is weak, because sometimes more than one specific act can lead to a certain arrangement. Another reason is that the classification in legislation can be history-based instead of purposeful. Largely, each law mentioned first regulates intramural services and personally bound care activities such as nursing. The second regulates support services; the support of informal carers, meals on wheels, transportation, aids etc. This leads us to assume that a rough distinction can be made in care and social support (legislation) as is also proposed in the Netherlands within the framework of the Social Support Act. Long-term care largely covers intramural facilities and extramural care concerning activities such as personal care, nursing etc. Social support covers all other services. Between countries the exact distinction slightly differs. Table 4.3 shows the presumed distinction.

Table 4.3; Distinction between Long-term Care and Social Support

Country	Distinction between (long-term) care and social support in legislation (care / social support)	Distinction between the degree of organization in the different acts on (long-term) care and social support (care / social support)	Distinction between funding of (long- term) care and social support (care / social support)
Netherlands	Yes (AWBZ/WVG-WW)	Yes (central/local)	Yes (premiums / central taxes)
Denmark	No (CASS)	No (local/local)	No (local taxes)
Sweden	Yes (HSL-LSS / SOL)	Yes (regional/local)	Yes (regional taxes / local taxes)
Germany	Yes (PVGS / DCSA)	Yes (regional/loca)	Yes (premiums / local taxes)
England	Yes (NHS/HSCA)	Yes (central/local)	Yes (central taxes / central & local taxes)

Referring back to the description of the different acts on long-term care and social support in the previous chapter, we can also conclude that care is generally organized centrally or regionally and social support always locally. As mentioned before, it is exactly this difference between long-term care and social support which is important if we want to investigate what we can learn from this for the development or implementation of the Dutch Social Support Act.

Compared to the other countries, especially Sweden, Germany and England, we can see that there are more services included in our AWBZ. This makes the Dutch proposal understandable. Especially considering that there is usually no legal right to care in the social support legislation, which make package limitations easier to handle in less prosperous times, this is a understandable direction (in the next section package limitations will be discussed). There is (probably besides Sweden) no country in the comparison which has so many large acts and legislation on social support. The proposal for two acts in the Netherlands is therefore not strange. It is, however, important to make a clear distinction between the arrangements that are covered by a certain act. If this distinction is unclear, as was the case between the NHS and HSCA in England, there is a risk that the responsibility for certain care or social support will be transferred to someone else (e.g. from the central fund of AWBZ to the local authority budget related to the Social Support Act).

As can be seen in table 4.3, local social support is largely funded by (local) taxes<sup>25</sup>. In the other countries (Sweden, Denmark), local authorities have a large freedom to set local taxes. In the Netherlands, however, this will not be the case. This makes it harder for the Dutch local authorities to implement the Social Support Act, because the local government cannot distinguish itself from another local authority on its tax level in connection with a certain service level (as will be seen in the following section). Also in England the ability of local authorities to vary their tax levels is quite strongly regulated by the central government.

Another difference, which may be important for the following comparisons, is whether there are different kinds of provider (public versus private) in long-term care as in social support. As table 4.4 shows, there is a minor difference. Whether a country has mainly private or mainly public providers largely depends on its history. This also means that it will not be able to change it in the short-term (if possible at all). This difference can have an influence on the following comparison if we suppose that working with public providers will lead to less far-reaching instrumentation because those who provide the service will be able to control it as well. We do not yet know whether this supposition is right, but it is important to keep it in mind while comparing in the next section.

Table 4.4; Distinction in Type of Provider concerning Long-term Care and Social Support

Country	Provision Care	Provision Social Support
Netherlands	Private providers	Private providers
Denmark	Mainly Public providers	Mainly Public providers
Sweden	Public providers	Mainly Public providers
Germany	Private providers	Private providers
England	Public providers	Public & Private providers

# 4.3 A Comparison of Specific Policy Objectives within Long-term Care / Social Support

### 4.3.1 Quality Related Objectives

#### **Quality Standards**

Table 4.5 shows if there are national quality standards for long-term care and social support. Quality standards are defined as guidelines *how to provide care* and on *what level of quality*. This means that standards concern the content and the implementation of delivered care and social support. For instance, a standard can be the obligation to use guidelines to prevent patients to get decubitus. The definition of quality standards in the five European countries is not uniform; the different standards focus on different items. Both public and private providers are subject to the standards and monitoring in a specific country. Despite the fact there is no uniform description of quality standards, we can see in the table that all countries have arranged something, mostly laid down in legislation. Sweden and the Netherlands do not have fixed quality standards; they have arranged quality of care in enabling legislation; it is up to the providers to fill it in.

<sup>&</sup>lt;sup>25</sup> The fact if long-term care is funded by taxes or by premiums is of no importance in our discussion and will therefore be left out the discussion.

Table 4.5; Quality Standards in Long-term Care and Social Support

Country	Standards for quality	Explanation and/or substitutes	Scope (care / social support / both)	Policy Instrument mix	Ι		1	(
Netherlands	No	There are central standards for patients' rights (BOPZ, WGBO) and for the service level (groene boekje), but no standards for the content and performance of care. There is a Care Institutions Quality Act (enabling legislation)	Care	Legislation (BOPZ, WGBO, Quality Act) and guidelines (service level)			+	
Denmark	Yes, local	There are local standards for the nature, scope and performance of care. Besides that are local standards for the service level	Both	Local legislation, central subsidies and central persuasion of local governments to implementat guidelines for delivering higher quality care, stable deliverance and efficiency	+	+	+	
Sweden	No	In the SOL there is a section on quality (enabling legislation)	Both	Legislation			+	
Germany	Yes, central	There is a central Care Quality Bill on the content and performance of care	Care	Legislation			+	
England	Yes, central (NHS) and local (SS)	The National Services Framework gives guideline on the quality of care and social support	Both	Guidelines on the content and performance of care and social support			+	

Germany and the Netherlands set standards or enabling legislation for long-term care, the other countries set standards or enabling legislation for long-term care and social support. The caesura between long-term care and social support as it is now in the Netherlands shows that the Dutch government has not intention at this moment to arrange anything concerning standards for quality within the Social Support Act. A comparison with the other European countries shows that they did not think it was wise to let go completely for the social support part. Literature and expert interviews has shown us that countries, who at first didn't arrange anything in terms of quality, Denmark and England, have returned on their steps when it became clear that quality of care in a decentralised system was a big problem. So, it seems to be wise for the Netherlands to arrange something on quality standards for social support on a central level. This does not mean that the Dutch government should set fixed quality standards, but to let go completely might be risky. However, for the past few years there has been an ongoing discussion in the Netherlands whether the Dutch Minister of Health should define quality standards for long-term care on a national level. So, maybe the time has come to end the discussion and formulate quality standards.

#### **Quality Assessment and Certification**

Quality assessment is defined as the use of quality (management) systems<sup>26</sup> (e.g. TQM). Certification can be defined as an assurance that quality of care is an important goal for care providers. An institution only gets certification if it can prove it is working according to established agreed-upon guidelines/procedures that can lead to good quality. Table 4.6 shows that the use of those instruments is largely on a voluntary basis. Local and central governments stimulate the use of those quality instruments with subsidies and occasionally with an agreement.

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<sup>&</sup>lt;sup>26</sup> Long-term care professionals have their own professional procedures for quality; this makes quality assessment and quality systems less important to guarantee a certain level of quality. Professional procedures and standards are described in section 4.3.2.

Table 4.6; Quality Assessment in Long-term Care and Social Support

Country	Quality Assess- ment	Certification	Explanation and/or substitutes	Scope (care / social support / both)	Policy Instrument mix		•	1	1
Netherlands	yes	Yes	Quality management system / certification voluntarily	care	Subsidies from the central government		+		
Denmark	No	Yes	Voluntarily certification	both	Subsidies from the central government		+		
Sweden	Yes	No	Quality assurance programme	care	Local (gentlemen's) agreements	+			
Germany	yes	No	Quality agreements in legal contract	care	Central legislation			+	
England	no	No							

Quality assessment is largely unspecified just as quality standards are, all countries organize it (if they do) in a different way. Most countries arrange quality assessment for long-term care, not for social support. Our conclusion based on this comparison is that the Dutch local authorities can take along quality assessment and certification in the agreements with long-term care and social support providers if local authorities want to assure quality of social support. Certification and quality assessment can also be stimulated through subsidies of other financial incentives, although it may be the most efficient if the central government promotes these. If each local government financially stimulates the development independently, this can lead to proliferation of probably conflicting quality systems.

#### Inspection

All countries, except Denmark for which we have insufficient information, have Inspection or a form of monitoring. Sometimes the focus of the inspection and monitoring is just long-term care, sometimes long-term care and social support. In case the focus is both, there are often more forms of inspection which show some overlap. In Germany, inspection is also carried out by a medical department of the insurance companies; a private actor. This comparison show that countries hardly dare to let go, and regulate nothing for monitoring. One can not be sure that it will be regulated by the long-term care and social support providers themselves, because it costs money and effort, which not always repays itself. Basically, the central or local government remains responsible for the quality of care. This responsibility can only be taken if there is also an organ which regularly checks the quality of care and social support. Not doing this makes government a slave of incidents. With regular monitoring government can avoid incident management.

Table 4.7; Inspection in Long-term Care and Social Supports

Country	Inspection	Explanation and/or substitutes	Scope (care / social support / both)	Policy Instrument mix	ļ	•	1	1
Netherlands	Yes	Central	Care	Inspection (Based on Quality Act and Health Care Act)				+
Denmark		?						
Sweden	yes	Central and regional: regional is County Administrative board (inspection nurse) and central is Nations Board of Health and Welfare	Both (central supervises HSL/LSS, regional the SOL)	Boards on monitoring and supervising (Based on HSL/LSS/SOL)				+
Germany	yes	Central	Care	Inspectorate of Ministry of Health				+
England	yes	Central; 2 inspections for long- term care and social care	Both	legislation				+

Quality of care and attitude towards patients are a regular focus of inspection in the various European countries, but it is difficult to get insight into what way inspection is performed or monitoring is arranged. For example for personal care, social support and person oriented guidance, it seems to be wise if the central government in the Netherlands lays down inspection within the Social Support Act. The comparison suggests that a national inspection works best. Local authorities should above all think how monitoring or inspection of social support tasks can be arranged on a local level. Sweden and England could serve as an example, because their inspection monitors long-term care and social support. Further investigation on this item is advised.

## 4.3.2 Quality of Professionals

#### **Professional Standards**

Table 4.8 shows that England in particular has arranged a lot concerning professional standards for care professionals. Historically, England always had explicit guidelines for professionals in health care. Codes of practice and guidelines now consider all professionals, in long-term care and social support as well. The National Care Standards Committee (Inspection) also concerns the standards for professionals. So, there is a link with inspection and professional guidelines.

Table 4.8; Professional Standards for Long-term Care and Social Support

Country	Professional standards	Explanation and/or substitutes	Scope (care / social support / both)	Policy Instrument mix	I	•	1	1
Netherlands	yes	Standards are self- regulation by professional groups, but the development is subsidized by central government	Care	Subsidies for standard development and agreements	+	+		
Denmark	?	?						
Sweden	?	?						
Germany	yes	?						
England	Yes	Central; Codes of Practice; Self regulation by the Royal College of Nursing*.	Both	The development is largely subsidized by the central government.	+	+		

Denmark and Sweden seem to have no special professional standards concerning their long-term care and social support workers. Again it is difficult to compare the content of the professional standards. If there are professional standards, these are largely nodality based and subsidized by the central government. In the Netherlands, the Minister of Health is keen on professional standards, but is not able to force professional care workers to agree. So, we agree within the well-known Polder model.

It seems to be wise for the Netherlands to aim at central professional standards for social support professionals as well. Especially for those who execute patient-directed actions. It does not seem feasible if standard development concerning social support workers will be subsidized by local governments. This can lead to fragmentation, and may result in the fact that it will be reached nowhere, whereas every local authority may think another local authority will profit as it did not help in the establishment (prisoner's dilemma).

Table 4.9; Regulation and Arrangements for Professionals in Long-term Care and Social Support

Country	Criteria for profes- sionals	Regi- stra- tion	Discipli- nary Board	Explanation and/or substitutes	Scope (care / social support / both)	Policy Instrument mix	1	•	1	(
Netherlands	yes	yes	yes	Central; There is a government registration body for professionals, the Individuals Health Care Professions Act and national education criteria Care* Gover registration legisla (acknowledge) (acknow		Government registration body and legislation (acknowledgement & education criteria). Legislation for the Disciplinary Board		+	+	+
Denmark	yes	?	?	National education criteria for nurses, social and health care assistants	Both	Legislation			+	
Sweden	yes	yes	yes	There are national education criteria for nurses, there is the Nation's Board of Health and Welfare, which deals with the registration of professionals. There is a National Medical Disciplinary Board for nursing	Care	Government registration body and legislation (acknowledgement & education criteria).			+	+
Germany	Yes	yes	?	Basic qualifications for nurses and legislation for the organization of registration	Care	Legislation for qualifications and registration			+	
England	Yes	yes	yes	National qualification criteria for all kinds of care and social support workers*. There are National Nursing Care and a Social Care Registers. Disciplinary Board	Both	Government registration body and legislation (acknowledgement & education criteria, disciplinary board).			+	+

Legend: \*The nurse assistants (level 1-3) are part of long-term care now, but will be part of social support in the future.

#### **Criteria and Registration of Professionals**

As is shown in table 4.9, educational criteria and the registration of professionals is well set for care professionals such as nurses in all European countries. European legislation concerning (health) care professionals plays a role here. This legislation is linked to the professionals and not linked to the type of social support or long-term care provider which they work for. Social support and long-term care workers not being health care professionals represent a different case. Denmark and England arrange criteria for social support professionals as well. Especially for those who execute patient-directed actions such as personal care or personal oriented guidance, this can be important.

Registration of professionals is less well organized. Sometimes it is arranged by legislation; sometimes the government organizes it themselves by setting up a government-managed register. In all five countries in our analysis, registration is centrally organized; it is not logical to organize the registration of social support workers on a local level because of the risk of large differences in policy.

## **Disciplinary Board**

There seems to be no disciplinary board in Denmark and Germany as is shown in table 4.9. And if there is, it only concerns long-term care workers. The question is if it is necessary to organise a disciplinary board for social support workers or care workers, not being a trained nurse. In Denmark, Sweden and England long-term care workers are largely employed by the local government. This probably makes it easier to address mistakes, and, for example, dismiss the professional concerned. There seems to be no clear line in how the five European countries organise disciplinary boards. If the countries organise anything, they organise it on a central level. The a priori question, however, is if it is wise to investigate the guarantee of the quality of long-term care workers and social support workers. As mentioned before, for those social support workers who execute patient-directed actions (such as personal care or personal-oriented guidance), this would probably be wise. It would also be wise to further investigate this topic.

#### 4.3.3 Innovation

Table 4.10 shows us that all five European countries stimulate the development of innovative projects in long-term care and social support; sometimes this is done on a central and sometimes on a local level. Only in the Netherlands, the focus of innovative programmes is on long-term care and not on social support. Those innovation programmes are mostly subsidized and very often resemble (central government) public-private partnership. In all countries, implementation of innovations is the biggest problem. Interviews with experts showed that when innovation is not started on a national level it doesn't spread out over the country. Innovation is often focused on efficiency, new concepts for care, and development of quality assessment instruments. Our conclusion is that with respect to the development of the Dutch Social Support Act, it is necessarily to continue the organization of innovative programmes on a national level and in the mean time to stimulate developments on a local level.

All countries also have National Advisory Boards which investigate the possibility for changes and innovation in long-term care and social support. Our advice to the Dutch Organisation of Local authorities (VNG, Vereniging Nederlandse Gemeenten) is to also install an advisory board to help them develop social support on a local level.

Table 4.10; Innovation Programmes in Long-term Care and Social Support

Country	Government Innovation programmes	Explanation and/or substitutes	Scope (care / social support / both)	Policy Instrument mix	1		1	(
Netherlands	Yes	There are central innovation programmes in care	Care	Mainly subsidies; there are agreements/covenant on PPP innovation projects.	+	+		
Denmark	Yes	There are central and local innovation programmes	Both	Mainly subsidies		+		
Sweden	Yes	Innovation programmes mainly financed by the central government	Both	Subsidies		+		
Germany	Yes	Innovation programmes mainly financed by the central government	Both	Subsidies				
England	Yes	There are central and local innovation programmes	Both	Subsidies and agreements/covenants for PPP innovation	+	+		

Table 4.11; Transparency in Long-term Care and Social Support

Country	Transpa- rency monitoring	Explanation and/or substitutes	Scope (care / social support / both)	Policy Instrument mix	_	•	1	1
Netherlands	Yes	Legal obligation on the Publication of Annual Reports. Voluntary benchmark.	Care	Subsidies for benchmarking. Legislation for publication of annual reports		+	+	
Denmark	Yes	Central government's database on price and quality of care. Local Monitors on price and Quality.	Social Support	Monitoring organization				+
Sweden	Yes	?						
Germany	Yes	?						
England	Yes	Pilots on performance measurements	Care			+		

## 4.3.4 Transparency

Table 4.11 compares transparency of price and quality of care information concerning long-term care and social support providers in the five European countries. This item concerns transparency so that government can evaluate the performance of the long-term care and social support system. Transparency for the clients is subject of section 4.3.5. All five countries use some tools to increase transparency. Based on the literature study and the interviews we can conclude that all countries consider transparency import, but that tools to improve transparency differ from country to country. Activities on gaining transparency are mostly initiated or organized by the central or local government.

Sometimes even local tools, like the implementation of local monitors, are an initiative of the central government. Most activities are directed at long-term care instead of social support. Only in Denmark and England, the focus is on social support as well. How well those monitors work is not clear. For instance, we do not now how much bureaucracy it costs to get information into the monitor. The responsibility for long-term care and social support in the end remains a Ministerial responsibility, so information about quality and price seems to be necessary to live up to this responsibility.

This leads us to conclude that the Netherlands, when implementing the Social Support Act, do need to invest in monitoring to gain transparency. It is wise to investigate on both the central and the local level; centrally to develop a specific set of data on which performance can be measured for the whole country (based on fields of performance); and locally to make it possible for local authorities to direct social support activities. To limit bureaucracy is a target of the current central government in the Netherlands. When developing these monitors, this is point of attention.

## 4.3.5 Client Centred Care

## **Special Right of Complaint**

As table 4.12 and 4.13, as well as the previous chapter on patients' rights, will show, in the Netherlands much is arranged with respect to the clients or users of long-term care and social support. The Netherlands have more legislation and treasury-based instruments to emancipate clients and users of care than the other countries in our comparison. The same is true for the right of complaint. The Netherlands is the only country that has special legislation for the right of complaint for long-term care. This Dutch Act for the Right of Complaint is focused on long-term care, and will therefore not be

Table 4.12; Right of Complaint in Long-term Care and Social Support

Country	Special Complaint right	Explanation and/or substitutes	Scope (care / social support / both)	Policy Instrument mix	I		1	1
Netherlands	Yes	Central Act for the Right of Complaint for Clients of the Care sector (care) and Administrative Law (social support) and Ombudsman (both, principles of good management)	Both	Legislation and Subsidies for guideline development and standardized procedures		+	+	
Denmark	No	Generic Administrative Law	Both	Legislation			+	
Sweden	No	National Administrative Court for complaints (specially needs assessment) and Ombudsman	Both	National Administrative Court				+
Germany		?	Both					
England	No	Local Patient's Charter and local authority complaint commission (first step) and afterwards National Health Service Commissioner (kind of Ombudsman) and a local authority ombudsman.	Both	Charter and subsidies for an Ombudsman		+	+	

in force for social support on a local level. In all the other countries, the right of complaint is part of a regular Administrative Law. In the Netherlands only, the social support sector falls under the Administrative Law. In addition, all countries have an Ombudsman.

Besides legislation, most countries also subsidize the development of complaints guidelines for example for needs assessment. In England, the right of complaint is often also described in the local patients' charters or citizen's charters. For the development of the Social Support Act, it is probably worthwhile to think about the right of complaint in advance. As in the future there may still be a right of complaint for long-term care patients, it does not seem logical to arrange nothing for complaints about social support. With the introduction of the Social Support Act, it seems strange that the organization of a right of complaint remains at the central level as local authorities themselves may determine what product package to offer or set their own eligibility criteria. Nevertheless, a central organization of the right of complaint is nowadays also the case for the locally executed WVG. Concerning the WVG, every year a lot of complaints are dealt with by the Ministry of Health, Welfare and Sports. On the other hand, a local authority's organization of a right of complaint may lead to arbitrariness.

Generic Administrative Law can be a solution, but this will probably lead to a run to go to court under administrative law. Local authorities can promote a right of complaint in Administrative Law as well. Local authorities can, for example, agree on a local complaints bureau or start an information campaign to stimulate citizens to file complaints. Such a complaint's policy can, for example, be part of the local authority policy documents. In conclusion, it seems advisable for local authorities to develop serious policy on a local 'right of complaint', and/or the central government can demand such an introduction of information policy in the Social Support Act. It seems easiest to join the Administrative Law for complaints into social support.

## Residents' Committees and Participation on a Local Level

In the Netherlands, there are lot of arrangements to stimulate client participation; especially for patients in intramural care<sup>27</sup>, specified legislation is enacted to stimulate client participation. Of the other countries in the comparison, England is the only one which also has special legislation to stimulate client's participation in the policy making by providers. Sweden and Denmark, however, execute both long-term care and social support on a local level, and therefore have probably arranged participation as integral part of local politics instead of arranging it on two different levels (central legislation for long-term care and local politics for social support). Looking at the Danish, Swedish and English solution for participation on social support, the Netherlands should also improve commitment of citizens to local politics when implementing the Social Support Act<sup>28</sup>. If this is aimed at, citizens have to be given the information and instruments to be able to participate. This means that the local government should arrange some meeting points, client counters etcetera to improve participation. It is also possible that the central government delegates the organization of client participation by the local authorities through enabling legislation. Local authority policy can be laid down in charters as is done in England or local authority policy booklets.

Table 4.13; Residents' Committees and Participation in Long-term Care and Social Support

Country	Residents' Committee	Participa- tion on a local level	Explanation and/or substitutes	Scope (care / so- cial support / both)	Policy Instrument mix	•	1	(
Netherlands	Yes	Yes	Care Institution's Clients' Right to Participation Act and part of the budgets of the Institution's. Regional patient platforms. There are subsidies for National Supportive Organizations for Resident Committees.	Care	Central Legislation and central financing through budgets and subsidies	+	+	
Denmark	No	Yes	Local authority Councils for Residents	Both	Organization			+
Sweden	No	Yes						
Germany	?	No	?					
England	Yes	Yes	Patient Forums (formerly Community Health Councils). Local authority Participation Forums (part of Citizen's Charters)	Both	Patient Forums are part of central NHS Legislation. Organization in case of Local authority Participation Forums		+	+

<sup>&</sup>lt;sup>27</sup> As can be seen in the following table, intramural capacity in the Netherlands is considerable compared to the other countries. Probably this is also the reason that there is much attention for participation for the intramural population. If they had been living among the population in living areas, participation should not have needed to get special attention. In countries where the extramuralisation is further developed as in the Netherlands, client's participation on a local or local authority level is expected to receive increasing attention.

Capacity of Lon	Capacity of Long-term Care for the Elderly							
Country	Absolute number of places for in the long- term care for the elderly (of which intramural)	Long-term care places per 100 persons age 65 and over (of which intramural)						
Netherlands	471.800 (200.000*)	20,8 (8,8)						
Denmark	170.000 (55.650)	27,3 (7,0)						
Sweden	301.000 (136.200)	19,9 (8,7)						
Germany	2.282.400 (979.500)	16,4 (6,8)						
England	England 997.900 (480.000) 10,6 (5,1)							
(Source: OECD I	Source: OECD Health data 2003							

<sup>&</sup>lt;sup>28</sup> This is also in line with the Project Overheid 2000, which tried to improve participation of citizens in the local democracy.

Table 4.14; Choice Supporting Information in Long-term Care and Social Support

Country	Choice supporting informa- tion	Client support Organiza- tion	Explanation and/or substitutes	Scope (care / social support / both)	Policy Instrument mix	_		1	(
Netherlands	No	Yes	Voluntary but subsidized (Michelin- guide) and through persuasion. Local Client support organizations (MEE)	Both (Michelin-guide for care and MEE for both)	Central government subsidies for the development of choice supporting information	+	+		
Denmark	Yes	Yes	Central government's database with Information about Institutions about price and quality	Social Support	Monitoring organization				+
Sweden	?	?							
Germany	No	Yes	Local Combined Service Units (= client supporting organizations)	Both	Subsidies for Service units		+		
England	?	Yes	Local client support organizations and telephone lines	Both	Local authority organizations				+

#### **Choice Supporting Information**

Of the five European countries compared in table 4.14, only Denmark seems to have arrangements concerning choice supporting information. It is organized by the central government. Study of the literature and interviews have made it clear that choice supporting information is not easy to arrange. Central governments are keen on having choice supporting information so they can speak of free choice for patients, but they seem unable to organise it. In all countries, a lot of talking and lobbying is done. There are some subsided programs, and there is hardly any legislation which enforces the provision of choice supporting information for clients. In Denmark, choice supporting information is focused on price and quality of long-term care and social support. Although there may be choice supporting information, it is the question if many clients of social support on a local authority level will change social support provider in small communities. Especially in smaller communities where there is little choice of providers, the question arises if choice supporting information is of any use for clients.

The goal of choice supporting information should be, in addition to free choice, to enable citizens to participate and communicate with local politicians (as was discussed in the previous section). Although there is sometimes no possibility to change provider, it is important to see how people's local authority is doing, also in comparison with other local authorities. In the Netherlands the central government has so far subsidized the gathering of choice supporting information for long-term care and development of databases. In the new Social Support Act, it should be the task of local authorities to arrange provider information. The central government should make an arrangement with the local authorities to do so. This arrangement can be part of the performance fields of the Social Support Act.

## **Client Support Organizations**

Literature and interviews suggest that almost all European countries in the comparison have client support organizations, sometimes organized by a local authority itself and sometimes only subsidized. Elderly and mentally handicapped often need help to organize the care and social support they need,

especially when the services they need are divided among more organizations and more financial regimes. It seems wise to organise it basically in a similar way for all local authorities. Local authorities should be critical which citizens can make use of it. At this moment, client support for the elderly is occasionally arranged on a local level, whereas client support for mentally disabled is organised on a national level (MEE Nederland) with local offices. It is advisable for the local authority to organise client support organizations on a local level with subsidies. Therefore it is also logical that client support organization will be transferred from the centrally organized long-term care to the locally organized social support.

## 4.3.6 Informal Care Support

In none of the five European countries there is a legal duty to provide informal care to relatives, parents or friends. As table 4.15 shows informal care support concerns both long-term care and social support. All European countries seem to realize how important informal care is. There are a lot of arrangements to support informal carers. Especially financial support and respite and relief care is well organised. Financial support is organised by national legislation and sometimes local implementation. In some countries, care leave is legally arranged. The Netherlands is the only country which has national organizations to protect the interests of informal carers. This probably due to our history and the fact that professional training and education of informal carers in the Netherlands is for the largest part organized by these organizations in stead of by government bodies themselves.

Table 4.15; Informal Care Support in Long-term Care and Social Support

Country	Legal bases informal care	Financial compens- ation infor- mal care	Care leave	Professio- nal training	Relief/ Respite facilities	Informal care orga- nization	Scope (care/ so- cial sup- port / both)	I	•	1	(
Netherlands	No	Yes (central, tax- deductions)	Yes (central, legislation)	No	Yes (central, facilities)	Yes (central, subsidies)	Both		+	+	+
Denmark	No	Yes (local, cash benefits)	Yes (central, legislation)	No	Yes (local, facilities)	No	Both		+	+	+
Sweden	No	Yes (local, grants & central legislation)	Yes (central, legislation)	Yes (local, facilities)	Yes (local, facilities)	No	Both		+	+	+
Germany	No	Yes (central, allowances & benefits, legislation)	No	Yes (local, subsidies)	Yes (central, facilities)	No	Both		+	+	
England	No	Yes (local grants )	No	No	Yes (central, facilities)	No	Both		+		+

Informal care is already mentioned as a performance field in the drafts of the Social Support Act. This means that informal care in the field of social support is a concern of the local authorities as from the introduction of the Social Support Act. From the perspective of the Social Support Act, this choice is logical. The consequence is that in the future informal carers have to deal with the central government for informal care in the domain of long-term care. When it concerns informal care in the domain of social support, they have to deal with the local authorities. It does not seem desirable to make different arrangements with informal carers in two different domains, which can be the case if personal care

remains within the AWBZ. The central government has to decide how informal care should be arranged in the future. Especially complex is the subsidy for informal care organizations. The central government needs to decide if it still wants to subsidize organizations, although it is just partially directed at long-term care or whether it also wants to decentralize this responsibility. Agreements on care leave and tax deductions should remain to be central governments decisions.

#### 4.3.7 Cost Control

As was described in the previous chapter, there are several ways to control costs. In table 4.16, it is indicated for the five European countries in this research which financial instruments are used. This table is slightly different from the previous tables, because all instruments are financial except for the needs assessment and therefore the last 5 columns focus just on the needs assessment. This table is also different because all fields explicitly interrelated to each other. For example: using no price setting with strict budgets causes eligibility to be necessarily small, since compensation limitation or needs assessment will therefore be important to prevent costs from rising above the budget maximum. As a result, the options need to be seen in connection with each other. While local authorities are given the freedom to decide on package and eligibility, it seems logical that cost control is performed at that level as well (he who pays the piper calls the tune). Broadly speaking, cost control regarding long-term care is organized centrally or regionally. Cost control for social support is organized locally.

Table 4.16; Cost Control in Long-term Care and Social Support

Country	Compensa tion limitations	Price setting	Budget regulation	User fees	Needs assess- ment	Others	Scope (care/ so- cial sup- port / both)	I	•	1	(
Netherlands	Yes (Central)	Yes (central)	Yes (central)	Yes (central)	Yes, central government body*	Transition points (central)	Both (welfare: no needs assess- ment)				+
Denmark	Yes (regional and local)	No (regional and local contracts)	Yes (regional and local)	Yes (regional and local)	Yes, local authority case manager	Freezing salaries (local)	Both				+
Sweden	Yes (regional and local)	No (regional and local contracts)	No	Yes (regional and local)	Yes, local authority care manager		Both				+
Germany	Yes (central and local)	No (central and local contracts)	Partially (care has central budget, social support nothing)	Yes (central and local)	Yes, central legislation	Flat rate budgeting	Both			+	
England	Yes (Central and local)	No (central and local contracts)	Partially (central/loc al, not for disabled/ informal care)	Yes (local)	Yes, central and local government body		Both				+

Legend: \* is at the moment local, as of January 1st 2005 it will be centrally organized.

#### **Budget Regulation**

Budget regulation will be continued when implementing the new Social Support Act. In Sweden, Denmark and England, local authorities can more easily raise their taxes than in the Netherlands as a result of the Dutch policy of a redistribution of wealth in which central government is the major player.

This makes the playing field of local authorities in the Social Support Act smaller than in the other foreign countries. Especially smaller when the fact is considered that it is not allowed to increase local taxes with the approval of citizens in order to provide a higher level of services<sup>29</sup>. In short, local authorities can only control costs and accessibility with the determination of the social support package, setting user fees, negotiation on purchasing prices and needs assessment (determination of eligibility).

## **Package Determination**

As to the determination of the care package to be delivered, Dutch local authorities will experience a limitation in the freedom of package determination because in the proposed Dutch Social Support Act some globally described performance fields are described. However, the exact determination of what will be done within the performance fields is the responsibility of the local authorities. This is logical if we consider the fact that he who pays the piper calls the tune. In the Netherlands, because of the relative large package that has been offered so far, this may encourage local authorities to cut down on the products they offer. The fact that package determination is the responsibility of individual local authorities has lead to inequality between different local authorities. In the other countries, this has caused many clients to go to court with their cases (especially in England). In the Netherlands, this is nowadays also the case concerning the WVG and Supplementary Benefits, but the Social Support act will lead to extra pressure on the courts. It is, however, the question if the courts are able to cope with the expected extra cases. The question which arises is if we want to be caught on the hop or if will we take measures beforehand. For the latter we can investigate the role of a special care court.

Another problem which can arise in the package determination is the fact that an even larger inequality arises when compensation of full-package care delivery (such as care and assistance and house help) is continued outside institutions within the scope of 'scheiden wonen-zorg', as the local authorities will not longer provide these. This inequality will probably be hard to explain to civilians and members of parliament.

## **Price Setting through Negotiation**

In the Netherlands prices have so far been determined by the central government. With the introduction of a functions-based funding of long-term care in the Netherlands, however, only maximum prices will be set. Looking at the other countries, this will be a wise decision because these have already introduced market prices in long-term care and social support.

#### **User Fees**

Only Sweden and the Netherlands know a maximal user fee, which are centrally determined. In Sweden the user fees is relatively low compared with the other countries. User fees need to be determined locally as was defined before. In the foreign countries in the comparison the separation between the own responsibility for living and the state's responsibility for receiving care

<sup>&</sup>lt;sup>29</sup> This development can be seen as contradictory: determining people's own eligibility may diminish the package to be delivered, and setting user fees also can have a huge influence on an individual's income and disposable income.

(extramuralisation) is further developed than in the Netherlands. This is visible in table 4.17 in the fact that for example the hotel function has to be paid by the occupant instead of that it is considered to be part of the care costs and partially subject to a user fee. In almost all countries when there is a lack of income to pay the user fees, there is the possibility to call upon the special security benefits (it is robbing Peter to pay Paul).

Germany also gives an interesting example regarding user fees. To control costs the German state only pays norm costs and everything above the norm costs, is the responsibility of the client.

Table 4.17: User Fees in Long-term Care and Social Support

Country	Means tested	Hotel function	Explanation
	User fee		
Netherlands	Partially	Yes, limited	User fee only means tested, not in relation with real costs.
Denmark	Partially	Yes, fully	Clients pay housing and cost for boarding. If no income then social security benefit (means tested)
Sweden	Yes	Yes, fully	Fixed maximum charge a day/year for the different types of care. Very low maximum user fee amount yearly.
Germany	Partially	Yes, fully	Client pays difference between norm costs for care and the real costs depending on the care arrangement. Clients pay housing and cost for boarding. If no income then social security benefit (means tested)
England	Partially	Yes, fully	Client pays the cost of living and when capital less then €30.000 social security benefit (means tested)

#### **Needs Assessment**

As can be derived from table 4.16 and 4.18 needs assessment can be organized by government herself (centrally or locally) or boarded out to private insurance organizations based on legislation (Germany). It is quite normal that government has a strong role on the needs assessment (performing it themselves or regulate it by legislation) if you consider the fact that it is also government which pays the long-term care and social support ('he who pays the piper calls the tune!). All countries installed a needs assessment to control the costs. There are no private bodies, like providers, who do not have to pay the care themselves that perform the needs assessment<sup>30</sup>. The facts that in Sweden, Denmark and England, however, government is for the largest part both provider and setter of the eligibility criteria makes that situation a little bit strange, but while she is still setting the eligibility criteria and controls her own employees this situation is regarded as similar as in the Netherlands. Needs assessment is performed on both care and social support, often in two separated procedures. It is advisable to the Dutch municipalities to keep a kind of needs assessment to control costs. There was not enough information on the availability of standardized needs assessment to be able to draw conclusions.

Looking at the social countries, such as Denmark and Sweden, it is apparent that those two countries do not take into account the availability of informal care during needs assessments. While informal care will still be taken into account in the Netherlands in needs assessments for long-term care, it is probably wise to keep it also in needs assessments for social support.

<sup>&</sup>lt;sup>30</sup> Although Dutch providers still do want the needs assessment, which was taking away from then beginning Eighties, back, this does not seem a good idea looking at the comparison.

Table 4.18; Needs Assessment in Long-term Care and Social Support

Country	Needs assessment dependent of informal care	Standardized assessments	Performed by	Scope (care/ social support / both)
Netherlands	Yes	Yes	Governmental Indication board	Both (except for welfare)
Denmark	No	Yes*	Municipal health visitor/social worker	Both
Sweden	No	No (local checklists)	Social worker aid executive	Both
Germany	Yes	?	Insurance boards	Both
England	Yes	No	GP (NHS) social workers (SSA)	Both (single assessment procedure implemented in April 2004)

Legend: \* Uniform pair of concepts

## 4.4 Summary

In this chapter, the five European countries have been compared on the basis of the topics determined earlier. In general, the conclusion can be made that the Dutch development towards the Social Support Act is not strange considering the situation in Denmark, Sweden, Germany and England. The organization of long-term care and social support in the five European countries show a lot of similarities, both in the use of policy instruments and in arrangements for long-term care and social support. Still, there are also some interesting differences, which can be important to consider for the Dutch central and local government when developing and implementing the new Social Support Act. For instance, the organization of monitoring and inspection for quality is of great interest. In the next chapter, this and other conclusions will be described and recommendations will be made.

# 5. Concluding Remarks and Recommendations

## 5.1 Introduction

This is the final chapter of this study. This means that it will be focussed on the answers of our research questions; the conclusions of our research project. Although these conclusions will more or less be indications instead of solid conclusions, some clues and/or recommendations for the development and implementation of the new Social Support Act can be given. As this is a tentative study, all conclusions, however, will possibly lead to further investigation. The second section of this chapter will focus on our research questions and the conclusions from our analysis. The conclusions use the research questions presented in chapter 1 as a guideline. The third section will discuss some limitations of this study. This last section will give some recommendations for further research.

## 5.2 Conclusions; Answering the Central Research Question

The central question of this study is to see what the Dutch government, both local and central, can learn for the development and implementation of the Social Support Act in the Netherlands from the policy instrument mix used to guarantee a certain level of affordability (cost control), quality and accessibility in the organization of long-term care and support in Denmark, Sweden, Germany and England. The aim is to pronounce recommendations.

To answer the above research question, a comparative analysis framework has been developed, based on the theory of policy instruments (second derived research question) and a translation of the values of 'control costs', 'quality' and 'accessibility' into specific policy fields which contribute to the achievement of these values (first research question). The latter translation has resulted in a focus on guaranteeing the development of quality standards and quality assessment, of supervision and inspection, of the quality of professionals, of the development of innovation, of the establishment of transparency, of the development of complaints management and the encouragement of participation (residents' committees and local authority participation), of the development of choice supporting information and the preservation of a certain level of cost control (needs assessment, user fees, price setting etc.), as well the growth to full stature of the support of informal care concerning social support. On all of these topics, indications can be given for the development and implementation of the proposed Dutch Social Support Act for both the central and the local government. We acknowledge a wealth of other interesting topics, but we have chosen to focus on investigating topics that get the most attention looking at the present organization of long-term care in the Netherlands. In future research, the list of topics may be expanded to other fields, such as admission of providers, the responsibility for the delivery of housing etc.

The second part of the comparative analysis framework is formed by the theory on policy instruments. This has made us select a comparison of four categories of instruments, based on Hood (1983) known as nodality based instruments, treasury based instruments, authority based instruments and

organization based instruments. The first can be seen as the group of communicative instruments, the second as financial stimuli, the third consists for the largest part of legislation and the fourth means that government will be the provider of the service itself. Each group consists of different instruments. For all topics mentioned above, we have explored for each country, *if*, *how* and *with which type of instrument* and if possible *which specific instrument* the objectives mentioned have been reached (derived research question 4). At the same time, each instrument is labeled according to whether it has been launched by the central, regional or local government. This distinction is important in the context of the proposed Social Support Act and seemed to be working reasonably. The difference between local and regional government was not always totally clear in literature, but after clarification by the interviewed people it became clearer. Altogether the framework allowed us to describe new information in a structured way.

Considering the use of Hoods policy instruments model and the use of this model in the comparison of the organization of long-term care we can make some comments. As mentioned in chapter two we left the detectors out because information on the detectors was incomplete and hard to get. When we filled the framework our conclusion was that we made the right choice. But for another reason than we mentioned in chapter two. During our analysis we came to the conclusion that the instruments used to influence long-term care policy often have a detector side themselves or can be seen as both; effector and detector. This is probably so because the government, central or local wants to know what is the effect of the use of such instrument. This means that cost control instruments are monitored, that inspection on care is established to make care-providers to work on quality as well as to monitor quality of care. Our study gave us the interesting understanding that using Hood's model, without taking into account the detector side, is no problem at all. This makes the study also scientifically relevant.

Another comment we can make on Hood's model is that when it considers care policy on a central or local level nodality based instruments are used almost always in combination with other policy instruments. Nodality based instruments are hardly be used as a single instrument to obtain a specific goal in long-term care or social support. As an example, to convince professionals to make their own standards, nodality based and treasury based instruments are used. So, for this policy field it seems hardly useful to look at nodality based instruments separately. This is probably due to the fact that concerning long-term care and social support government wants to reach society broad policy goals, whereas the consequences of the policy goals always directly have impact on the individual. Solely using communication or nodality based instruments will not persuade the client to the desired action, while the client will reason for his/her own best well-being in stead of societies well-being (prisoners-dilemma). Hood's other instrument categories have a more forcible character and will therefore be better applicable. This leaves us with the idea that in our long-term care and social support or other similar cases Hood's model is especially applicable when looking at the treasure, authority and organization based instrument categories. In our opinion, this can be seen as a methodological scientific relevant outcome of our study.

As we were interested to see what we could learn for the development of the Social Support Act, we have made a differentiation to see if the instrument set used was directed at long-term care and/or social support in the different countries. To be able to do this, we had to describe some general features of the long-term care and social support system and policy in the different countries (derived research question 3). This has resulted in a preliminary arrangement of products to be delivered in long-term care and social support. The availability of a clear comparable distinction between long-term care and social support in the different countries is, however, a weak spot of this study, because the delineation in the package to be delivered as well as the organization and legislation on which package delivery is based differ largely between the countries (for this and other limitation of the research, see next section). As to the description of the long-term care and social support policy in the Netherlands, Denmark, Sweden, Germany and England and the translation of the description in the comparative analysis framework, we refer back to the descriptions of all countries and their comparisons in chapter 3 and 4 respectively.

In *general* we can conclude from this study that the development of the Dutch Social Support Act is not an unexpected development. Almost all countries in the comparison, more or less, have different regulations for social support and long-term care (except for Denmark), even though the definition of the target group for long-term care and social support is different in all countries; sometimes psychiatric patients do belong to the target group, sometimes they do not. Most of the time, the chronically ill are not mentioned specifically at all. For both groups, the reason for this is that they are largely placed in a curative sphere. We can also conclude that care is more or less organized centrally or regionally and social support always locally. The local execution of social support is largely funded by (local) taxes (except in the Netherlands).

Compared to the other countries, we can also see that more services remain in our care act (AWBZ) than in the other countries, especially Sweden, Germany and England, which offer most of these services as social support<sup>31</sup>, e.g. client support organizations (similar as MEE). At the same time, all countries have focused on affordability during the past few years. This has led to the fact that packages in the other countries have been reduced over the past few years. This is a result of a continuous trade off between quality and accessibility against affordability. As this is easier under a law under which there is no right of care such as the Dutch Social Support Act, this makes the Dutch proposal understandable.

We can also conclude that countries are fairly similar in their set of instruments used for the organization of long-term care and social support. In the mean time, the exact interpretation of policy topics may be totally different. Although a lot of information can be found on the organization of long-term care and social support in these countries, it is hard to determine if the system really works the way it is stated. This has made it difficult to reach clear conclusions, but some interesting **specific** suggestions can be made.

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<sup>&</sup>lt;sup>31</sup> Nevertheless, it can be possible that we know more about our own situation than we will ever know about the other countries investigated (bias).

All countries have at least some arrangements for quality standards, mostly laid down in authority based instruments, especially legislation. A comparison with the other European countries shows that they did not believe it was wise to abandon quality standards completely for the social support part. Arrangements made for quality assessment and certification are quite divers in the different European countries. If there are arrangements at all, they are treasury based, voluntary and mostly part of contractual agreements with providers. All countries also have some form of inspection, sometimes organisation based. The comparison has shown that countries hardly dare to hand over control and regulate nothing for monitoring. So, they organise it themselves or they make sure it will be organised by putting in treasury based instruments. The organization of innovative programmes is laid down on a national level in all countries. Mostly treasury based instruments are used to stimulate innovation. The responsibility for policy making can be on a local level. This teaches us that it is necessary to stimulate developments on a national level, for instance with help of subsidies. All countries consider transparency as an import thing, but the tools to improve transparency differ from country to country. Activities on gaining transparency are mostly initiated or organized by the central or local government. Sometimes the implementation of local monitors is an initiative of the central government and is organized with treasury based instruments.

In all countries, registration and education criteria for professionals are authority based instruments, centrally organized; it is not logical to organize criteria for the registration and education of social support workers on a local level because of the risk of large differences in policy. Only part of the social support workers are subject to registration and educational matters. Some of the European countries work with national professional standards concerning long-term care and social support; most of them are stimulated by treasury based instruments such as subsidies.

As for client related aspects of long-term care and social support, only in the Netherlands an authority based instrument such as a legal right of complaint exists. In all the other European countries, the right of complaint is part of Administrative Law. Sometimes additionally, local authorities have arranged the possibility to launch a complaint through an organization based instrument as a special local authority office or committee. Client participation within a residents' committee is legally arranged within the Netherlands, unlike any of the other European countries. Some countries, such as England and Denmark, work with an organization based instrument as a client health care committee on a local level. Although choice supporting information is not easy to be arranged, all European countries agree on the fact that the availability of client supporting information for their citizens is important to make free choice possible. The comparison shows us that till now, central and local governments have seemed to be unable to settle it, even though in all the countries, there is a lot of talking and lobbying. All the European countries in the comparison seem to have client support organizations, sometimes organized by the local authority itself, and sometimes stimulated by treasury based instruments such as local subsidies.

All European countries seem to realize how important informal care is. There are a lot of arrangements to support informal carers. Especially treasury based instruments such as financial

support or organization based respite and relief care, are well arranged. The cost control of long-term care is most of the time organized centrally or regionally, while cost control concerning social support is organized on a regional or local level. All countries work with a organization based instrument as a needs assessment. Social support is mostly locally organized, and it is also the local government that uses its authority to set eligibility criteria except for Germany, where there is legal delineation and definition of long-term care. As the local authorities in the Nordic countries (Sweden and Denmark) have a larger freedom to set local taxes, it is easier for them to distinguish themselves from another local authority on their tax level for a certain service level.

A problem that has come up in England, Sweden and Denmark is a lack of integrated care. Especially in England and Sweden there is a big gap between health care and long-term care. The consequence of this is that people get a certain package of care without knowing what their illness or problem is. People suffering from Alzheimer's disease do often get the wrong package of care. A lack of coordination is part of this problem as well, some countries introduce a local case manager to create coherence between social support and long-term care.

An interesting aspect of our study is also that even without evaluating the performance of the system and the described instruments we were able to draw conclusions just on the basis of a description of the system and the policy instrument mix. We were not sure beforehand that this could lead to interesting conclusions, but in practice and if you look at the analysis in chapter four and the conclusions above you can conclude that the framework was useful.

#### 5.3 Recommendations

With the framework completed, we can derive some recommendations of particular interest for the central government concerning the development of the Social Support Act (derived research question 5). As was described in the introduction of this study, the Dutch central Government did not want to arrange nor establish rules or guidelines for the execution of the Social Support Act. This study, however, has shown that there are fields which may demand the attention of the central government. Looking at what has been arranged in the other countries, it might be a bit risky to abandon complete control of these issues, knowing that the central government always keeps a certain responsibility and can be called to account. This insight makes this study both social as well as scientifically relevant. These fields are, for example, the development and stimulation of quality standards and quality assessment for the Social Support Act. In general, the development of innovation, projects to improve the quality of care, to improve transparency (minimal selected dataset), which most of all will not be performed voluntarily by the social support providers (or local authorities) themselves, need to be controlled by the central government. The central government can best arrange this by subsidies or as a result of enabling legislation (aimed directly at the providers, or, probably even better, to force local authorities to act). If it is left to local governments, improvements will be very diverse, diffusion of best practice will probably take place slowly or the other way around if diffuse; every local authority will wait till someone else has invented something (prisoner's dilemma).

The same will be true for inspection and monitoring; without anything arranged for inspection, this will make the central government a slave to incidents involving quality of care. Also on the development of professionals, such as professional standards, education criteria, registration of social support workers (mainly personal assistants when this will be transferred to the Social Support Act), and the development of disciplinary boards, the central government needs to play a role. If only because the central government still needs to arrange the same things for long-term care.

Another problem which can arise is the fact that an even larger inequality arises in the determination of care packages when central government will continue the compensation of full-package care delivery (e.g. including personal care and house help) outside institutions within the scope of 'scheiden wonenzorg', as local authorities will not longer provide these. As this may lead to involvement of the House of Parliament in packages delivered, it may be worthwhile if a central government rethinks its policy on this issue.

Considering the possibility that in the future there will still be a right of complaint for long-term care patients, it seems illogical to arrange nothing for complaints in the field of social support. It seems advisable for the central government to demand the set-up of a complaints organization or information policy on complaints by a local authority at the introduction of the Social Support Act. It seems easiest to join the Administrative Law for complaints on social support. It is, however, a question if the courts are able to cope with the expected extra cases. The question which arises is whether we want to be caught on the hop or to take measures beforehand. The latter seems to be advisable; starting an information campaign aimed at the law courts may be the simplest action to take. The central government should probably also make an arrangement with the local authorities to arrange choice supporting provider information. This arrangement can be part of the performance fields of the Social Support Act.

The central government needs to decide whether it still wants to subsidize informal care organizations, as these are just partially directed at long-term care or to decentralize the responsibility of the organization of support services for informal carers in the social support sphere as well. Agreements on care leave and tax deductions should be continued as decisions of the central government.

The central government does not need to arrange something for cost control, which is not yet taken into account (such as maximum user fees and budget regulation).

For the Dutch *local authorities*, we can also make several recommendations for the implementation of the Social Support Act (derived research question 6). Local governments can guarantee the quality of social support by including quality assessment and certification in the agreements with long-term care and social support providers. Above all local authorities should also think how they can monitor or inspect social support tasks. Sweden and England with inspections for both long-term care and social support can be used as an example. Further investigation into this matter is advised. Monitors to

increase transparency need also be developed by local governments; if not, it will not be easy for them to assess providers of care in a right way with the risk of getting a worse price-quality ratio in price agreements. To stimulate developments on innovation on a local level, the Dutch Organisation of Local authorities (VNG, Vereniging Nederlandse Gemeenten) is advised to install an advisory board to help develop social support innovation on a local level.

It seems advisable for local authorities to arrange some serious policy on a local 'right of complaint'. At the same time, there is a task for local government to arrange participation on the care to be delivered. To be able to meet this performance field, local governments should arrange some meeting points, client counters, etcetera, to improve participation of social support users. Clients, however, need information to be able to participate. In the Social Support Act, it should be the task for the local authorities to arrange choice supporting provider information for clients. Local authority policy on these issues can be laid down in charters like in England or local authority policy booklets.

As local authorities are given the freedom to decide on package and eligibility, it seems logical that cost control is performed at that level as well (he who pays the piper calls the tune). Since Dutch local governments are not allowed to increase local taxes, this makes it harder for them to execute the Social Support Act than in the other European countries. This is due to that fact that local governments cannot distinguish themselves from other local authorities on their tax level in connection with a certain service level. In short, local authorities can only control costs and accessibility with the determination of social support packages, setting user fees, negotiating purchasing prices and needs assessments (determination of eligibility). We regret that this study has not lead to the determination of a kind of minimal package to be delivered which the government could have considered when defining their package. It is advisable that local authorities make price and quality arrangements with social support providers, because the other countries in our study have already introduced market prices in long-term care and social support. So it is advisable for the Dutch local authorities to keep a kind of needs assessment to control costs. Such a needs assessment must be the responsibility of a local authority, and does not need to be described in the performance fields of the Social Support Act. It is, however, worthwhile if the local governments take the delivery of informal care into account in needs assessments. This should be in line with needs assessments for long-term care.

## 5.4 Discussion and Further Investigation

The main limitation of this study is the determination of the dividing line between cure and long-term care and between long-term care and social support successively. Both distinctions are difficult to make because of the differences in the organization, the legal basis and the packages offered as part of the curative medicine, long-term care and social support. This unclear delineation has lead to problems in the organization of cure, care and social support in several countries. In England, this has lead to shifts in responsibility from cure to care, from care to social support and the other way round.

Secondly, this study is aimed at learning from other experiences for the benefit of the development and implementation of the new Social Support Act. This means there is a need to look at country-specific information in two ways. Firstly unbiased to see what really happens (chapter three), and secondly biased because we needed to take the distinction between long-term care and social support as a starting point to be able to draw conclusions. The dividing line between long-term care and social support which is then taken as starting point is biased and ambiguous. This bias and unclear distinction make the conclusions drawn on this distinction less strong, even though some conclusions still can be drawn. The determination of the topics under investigation is also largely biased, because we are looking at topics which we determine as important in the Netherlands; in another country, however, it is possible that other tools and policy areas are determined as important in order to achieve the same aims as in the Netherlands but in a different way. We have tried to by-pass this bias by describing also other substitutes in which a policy objective may be reached. At the same time, it must be clear that the list of substitutes is far from complete. Looking at the policy objective from a neutral viewpoint, or successively from every foreign country could have improved this study.

During our study, we have had to conclude that there is a lot of information on care for the elderly in the different countries, but that the description of care for the disabled and psychiatric patients seems to be incomplete. Sometimes we expected a difference in the execution of a policy (care package) on the disabled and the elderly, although we were not able to derive this from the literature. This can result from the fact that there is no difference, or because there is no information available. As so much information on these target groups is unavailable, it is hard to draw solid conclusions about the performance of the policy. It would be interesting to see if we could draw different conclusions if more information had been available on these specific target groups. We suggest further more evaluative than prescriptive investigation into this area. Further research is also recommended to see what exactly went wrong in the transfer of Swedish long-term psychiatric care. In relation to a transfer of extramural and intramural short-term (shorter than a year) (psychiatric) AWBZ-care into the Health Insurance Act, further investigation of especially psychiatric care in Germany and Sweden, but also the other target groups, can be interesting as well.

When making the analysis, it became clear that the nodality-based instruments were not easy to handle and investigate. To achieve almost all policy objectives, forms of communication are used, if only to gain a better understanding of the policy issue by the parties involved. All countries do so, and this makes the comparison of this category nearly impossible. This category is therefore only mentioned when there is a real difference in the way of handling between the countries. It might, however, be interesting for another study to investigate whether the nodality-based instruments are used in the different countries in a similar way, or that some countries prefer specific instruments (e.g. gentlemen's agreements or information campaigns). However, this was beyond the scope of this research. Secondly, further research is needed to find other factors that influence the mix of policy instruments.

As was described in the second chapter of this research paper, the detectors which were also part of the instrument categorization according to Hood (1983) were left out of this research project because we had to narrow our scope. The consequence of this is that there is only limited information about the information on which the governments in the different countries base their decisions. To take along the detectors-side of the arrangement of Hood in ensuing research can therefore be interesting, but as we concluded in section 5.2 is not explicitly needed.

The selection of the countries with a view to the welfare state and governance model of long-term care seemed to emphasize long-term care and less social support. It is probably interesting to extend research with countries which show more differences in the level of social support services, although these might be hard to find in the West European countries with their high standards of packages. A comparison in which also the United States is included may give another interesting comparison. Although the American system is in basically very different, the outcome on specific (policy) fields makes the system worth to investigate. However, it has become clear that the fact that we always want to compare ourselves to the Scandinavian countries is not very logical, because considering the development of the Dutch Social Support Act we probably resemble England more than the Nordic countries. In any case, the fact that local governments in Denmark and Sweden are most of the time both regulators and providers of care and social support makes the comparison difficult. This gives a wholly different starting point. This has also made us decide not always simply to adopt the Danish and Swedish solution, but also to take into account the feasibility of a particular Danish or Swedish solution in the Netherlands situation.

# **Glossary**

#### **Administrative Care Office**

These offices, which operate on a regional level, are responsible for all administrative tasks resulting from the AWBZ (for example the purchase of care and consultation between parties involved)

## **AWBZ**

In the Netherlands, most long-term care is financed by special taxes under a social insurance law, called the General Exceptional Medical Expenses Act.

## **Choice Supporting Information**

Choice supporting information enables patients to make a well-considered choice which long-term care and social support provider they choose for the care and support they want. In the Netherlands, choice supporting information is translated into a "Michelin-guide".

#### Complaints' Right

In the Netherlands, a legal right of complaint is laid down in the Dutch Act for the Right of Complaint of the Care Sector. This Act deals with the possibility to appeal through official complaints committees.

## Home adaptations

Functionally impaired people are entitled to adaptations of their homes in order to live as independently as possible. This also applies to many elderly people. People can apply to their local authority for grants for housing adaptations.

#### Home help

When elderly people are no longer able to take full care of themselves in the home, they can receive home help

## **Individual Budget (PGB)**

A person receives a sum of money or a bond -a voucher- as a means for payment for public service (upon the consent of the RIO, see Regional Assessment Board). With the PGB, people have a choice of doing the negotiations themselves with providers about care arrangements and related prices.

#### **Informal Care**

Informal care is provided by relatives, friends and others who are not professionals and who provide this care on a voluntary basis, so they are not employed by a care provider.

#### Innovation

Renewal and modernization of long-term care and social support often concern new concepts for care

or social support, new technological innovations and so on.

#### Inspection

Inspection supervises health assess the quality of care, advise government, and sometimes if necessary, close down nursing homes or care homes if the quality is found to be unacceptable.

## **Long-term Care**

According to the Health Care Institute Washington DC, long-term care is defined as a variety of ongoing health and social services provided for individuals who need assistance on a continuing basis because of physical or mental disability. Services can be provided in an institution, the home or the community, and include informal services provided by family or friends as well as formal services provided by professionals or agencies.

#### Meals on wheels

All local authorities can offer the distribution of ready-made food at cost price to elderly people in both regular and special housing. A formal decision by a local authority is required for this service to be provided.

#### **Needs Assessment**

Accessibility of care and social support is arranged on a basis of needs, assessed in a standard way, based on eligibility criteria laid down in legislation on a local or central level.

## **Personal Safety Alarms**

Personal safety alarms to elderly and functionally impaired people living in regular housing, connected with an alarm centre.

## **Professional**

Nurses and doctors are (health) professionals educated on the basis of a set criteria, registered in a register for health care professionals and subordinate to a medical disciplinary board.

## **Quality Assessment**

To assure a certain level of quality of care and services, quality management and certification are common instruments, used by care providers.

## **Quality Standards**

Quality standards can be seen as agreed upon standards by government, professionals, insurance companies and care and social support providers concerning the content and/or the execution and/or the obliged use of guidelines of care and social support delivered.

## Regional Assessment Board (RIO)

Government body responsible for determining the type and amount of need in response to a request for care.

## **Transportation Service**

Elderly and functionally impaired people who are no longer able to use regular public transport are entitled to a transportation service. The most common form of transport is a taxi, but special buses are sometimes included.

## WVG

The provisions for the Disabled Act cover the provision of care facilities such as transportation, housing adjustment and wheelchairs.

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# Appendix 1 Questionnaire for Data-gathering and -analysis

## **Definition of Long-term Care and Social Support**

- Is there any (formal or legal) definition of long-term care and /or social support specifically used in the country under investigation?
- If not, is there any other definition which is often used?
- What is the definition used in the country under investigation on long-term care and social support?

## **Objective of Long-term Care and Social Support**

 What is the (formal or legal) objective for long-term care and social support in the country under investigation?

#### **Target Group**

What are the target groups for long-term care and social support?

#### **Long-term Care and Social Support Arrangements**

- What is the content of long-term care and social support? Which services and products are provided? Which are considered as 'Long-term care' and which as 'Social Support'?
- Which legislation arranges those services and products?

## **Legal Framework and Financing**

Which legislation is the basis for long-term care and social support systems and the financing of the system?

#### **Actors**

• What are the actors in the field of long-term care and social support? Especially the actors which organise and formulate policy (operational and policy making responsibility)?

#### **Quality Standards**

- Are there any national quality standards in the area of long-term care and social support in the country under investigation?
- Do these standards reflect the content of the care and social support and/or the execution and/or
  the use of guidelines regarding the quality of care and social support? If so (as a check), what do
  these national standards contain and/or measure: level of services, way of deliverance, quality of
  output, quality aspects on the professionals delivering the care of something else?
- Are these quality standards defined by government, professionals, insurance companies and providers?

- Do the standards reflect long-term care or social support? For example, products which are not really care (like meals on wheels etc.), are they part of the quality standards as well?
- Are these standards implemented by local / regional or central government? Which instruments does which government level use to stimulate/implement/guarantee the quality standards? For example, are there any financial or other sanctions when quality does not meet the quality standards or are there any subsidies or other monetary stimuli for improving the quality on a local/regional/national level?

#### **Quality Assessment**

- Do the care and social support providers use quality management systems, such as TQM, management information systems to assure the quality of delivered services?
- Do the quality assessment systems reflect long-term care or social support?
- Is the use of these instruments stimulated or requested by government (central/regional/local)? H
- Is certification used by care and social support providers?
- Does certification reflect long-term care or social support?
- Is it done voluntary or stimulated or requested by government (central/regional/local)?
- Which instruments does which government level use to stimulate/implement/guarantee the use of quality assessment instruments and certification?

#### **Professionals**

- Is there any legislation concerning health care professionals? What doest it say?
- Are there any unskilled long term care helpers (not being informal carers)? What kind of work do these people do?
- Is there a difference in professional standards for long term care helpers who provide care and those who provide Social support which are not really care (house help or social support)?
- Does government (central/regional/local) stimulate (e.g. persuasion, subsidies, legislation, or by organization by government) the development of professional guidelines?

## Innovation

- Is innovation in long term care and/or social support stimulated in your country?
- If so, by whom (central/regional/local government) and how (e.g. with legislation, financial incentives, persuasion and covenants etc.)?
- Are there innovation programmes for both long-term care and social support?
- Are there advisory boards on (the development of) long term care issues or knowledge institutes?
   Are they organized by government (central/regional/local) or are these private or public?
- Does government (central/regional/local) stimulate (e.g. persuasion, subsidies) innovation?

## **Transparency**

 Is transparency on e.g. price and quality part of policy making in long term care and social support?

- Is there a difference concerning transparency objectives in long-term care and social support?
- How is gaining transparency organized? Are there guidelines, aimed at gaining transparency, laid down in legislation (central/regional/local)? Does the government (central/regional/local) use benchmarking or similar tools to evaluate the performance of service providers?
- Does the government (central/regional/local) stimulate transparency and with which instruments (e.g. persuasion, subsidies, legislation)?

#### **Complaints Organization**

- Is there something arranged on complaints for clients in the specific country?
- Is there a difference concerning the organization of complaints in long-term care and social support?
- Is there any central/regional/local legislation on the organization of complaints (complaints from the patient about the delivery of care)?
- Are any forms of complaints measurement and complaints handling in some way stimulated in your country? Or is it normal that you go to the 'judge' or ombudsman with your complaint? What is the procedure? What is the task of the local government?
- With which type of instruments (e.g. with legislation, financial incentives, persuasion, a central complaints register etc.)?

## **Residents' Committees and Local Participation**

- Are their residents' committees in which patients that receive care from an organization have a say in matters concerning the quality of care, the waiting time etc.?
- What is the task of the residents' committees on a municipal level?
- Does government (central/regional/local) stimulate these?
- Is there a difference in long-term care and social support on this subject?
- How does the government stimulate (e.g. persuasion, subsidies) and to what extent (e.g. which kind of institution there is a resident committee and where not etc.)?
- Is there any form of participation by (potential) clients and citizens on the local (municipal) social support policy?
- Which instruments does which government level use to stimulate/implement/guarantee the local participation of citizens or clients (legislation, subsidized etc)?

#### **Choice Supporting Information**

- Does the government (central/regional/local) provide choice supporting information to potential care demanders for example to enlarge the freedom of choice? How (e.g. persuasion, subsidies, legislation)?
- What kind of information is it? Who is responsible for collecting the information and who collects?
   How is the information supplied, by one office which can give you all the information you need as a civilian?

- Are there organizations that support the clients to make a choice on their delivery of care (the 'products') and the providers? Has government a role in setting up or maintaining these organizations? How (e.g. persuasion, subsidies, legislation)?
- Do long term care organizations measure patient satisfaction and do social support organizations?
- Does government (central/regional/local) stimulate patient satisfaction measurement? How (e.g. persuasion, subsidies)? And to what extent (what subjects are measured and how often)?

#### **Cost Control**

- What instruments are used to control long term care expenditures? Are they defined by law, are there any financial incentives etc.?
- Which government level (central/regional/local) uses the cost control instruments?
- Are there differences between long-term care and social support?
- Are there fixed prices set by the central or local government (price settlement)?
- Is provision of informal care taken into account at the needs assessment?
- How is the needs assessment organized? Is the needs assessment organization a government office or a private/semi-public institution or are other instruments used to stimulate the needs assessment?
- Is it possible that a person needs to go to two needs assessment organizations (local/regional) for different parts of his/her care? If so, how do these organizations then work together?
- Is there a highest level of services/health care you can be entitled to?
- Is there a limitation to the compensation which an individual person can receive (on his entitlement)?
- Is there any form of compensation possible for high expenses or user fees concerning care? If people are not able to manage to pay their rent in e.g. a adapted dwelling, their transportation services, meals on wheels etc., is there a social assistance benefit that can support the individual?

#### Informal care

- Are there any regulations on the support for informal carers / family care in the form of a (paid/unpaid) care leave policy/legislation?
- Is there a difference between family care and volunteers in the form of (paid/unpaid) or care leave?
- Is there a minimum level of informal care that you have to deliver before you can make use of any of the above mentioned support services?
- What other ways of support are there for informal carers: Respite/relief services? Allowances? Tax deduction? Training?
- How does the government (central/regional/local?) organize (e.g. persuasion, subsidies) and to what extent?
- Is there a difference between informal care support in long-term care and social support?

# **Appendix 2** Interview Survey-questions

## Quality

- Are there national standards regarding the quality and accessibility of care and social support? If so, what do these national standards contain and/or measure: level of services, way of deliverance, quality of output, quality aspects on the professionals delivering the care of something else?
- Is there any other form of inspection organized on a local / regional or central level? What do they monitor? Do they check measured performances on quality standards?
- Products which are not really care (like meals on wheels etc.), are they part of the quality standards as well? Are they part of the inspections as well?
- Are there any subsidies or other monetary stimuli for improving the quality on a local/regional/national level?
- Are there any financial or other sanctions when quality does not meet the quality standards?
- Do care and social support providers use quality management systems, such as TQM or management information systems to assure the quality of delivered services? Is the use of these instruments stimulated or requested by the government (central/regional/local)? How?
- Is certification used by care and social support providers? Is it done voluntarily or stimulated and/or requested by the government (central/regional/local)?

#### Health care and social support professionals

- Is there any legislation concerning health care professionals? If so, what does it cover?
- Are there any unskilled long-term care helpers (not being informal carers)? What kind of work do these people do?
- Is there a difference in professional standards for long-term care helpers who provide care and those who provide other products which are not really care (house help or social support)?
- Does the government (central/regional/local) stimulate the development of professional guidelines? How (for example persuasion, subsidies)? And to what extent?

#### Innovation

- Is innovation in long-term care and social support stimulated in your country? If so, by whom (central/regional/local government) and how (e.g. with legislation, financial incentives, persuasion and covenants etc.)?
- Are there advisory boards on (the development of) long-term care issues or knowledge institutes? Are they organized centrally/regionally/locally? Are these private or public? Are these financially supported by the government (central/regional/local)? What is the task of the local government?

## **Transparency**

- Is transparency on for example price and quality part of policy making on long-term care and social support? How is gaining transparency organized? Are there guidelines, aimed at gaining transparency, laid down in legislation (central, local)? Is it subsidized and by whom (central/regional/local government)?
- Does the government (central/regional/local) use benchmarking or similar tools to evaluate the performance of service providers?

## **Organization of complaints**

- Clients seem to be able to complain about requested services: is the administrative court part of the Court or is it a special court for complaints about long-term care?
- Is there any central/regional/local legislation on the organization of complaints (complaints by the patient about the delivery of care)? Are forms of complaint measurement and complaint handling as part of patients rights in some way stimulated in your country (e.g. with legislation, financial incentives, persuasion, a central complaints register etc.)? Or is it customary for people to go to the 'judge' or ombudsman with their complaint? What is the procedure? What is the task of the local government?
- Is there a special legal organ/court concerning health care cases?

## Client Involvement in Policy; Residents' Committees and Local Participation

- Are there resident committees in which patients that receive care from an organization have a
  say in matters concerning quality of care, waiting times etc.? Does the government
  (central/regional/local) stimulate these? How (e.g. persuasion, subsidies)? And to what extent
  (e.g. which kind of institution there is a resident committee and where not etc.)?
- What is the task of the residents committees on a local level?
- Do (potential) clients have influence on local (local authority) social support policy? If so, how is it organized? Is it laid down in legislation, subsidized etc.?

## **Choice Supporting Information**

- Does the government (central/regional/local) provide choice supporting information to potential care seekers, for example to enlarge the freedom of choice? How (e.g. persuasion, subsidies, legislation)? What kind of information is it? Who is responsible for collecting the information and who collects? How is the information supplied, by one office which can give people all the information they need as civilians?
- Are there organizations that support clients in making a choice as to their delivery of care (the 'products') and the providers? Has the government a role in setting up or maintaining these organizations? How (e.g. persuasion, subsidies, legislation)?
- Do health care organizations measure patient satisfaction? Does the government measure client satisfaction? Someone else (patient organizations)? Is it compulsory to measure this?
   Does the government (central/regional/local) stimulate patient satisfaction measurement? How (e.g. persuasion, subsidies)? And to what extent (what subjects are measured and how often)?

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#### Patient rights

Are patients' rights defined in legislation? On medical assessment? On equal rights?
 Involuntary admission? What incentives are there to adhere to these laws?

#### Cost control

- What instruments are used to control long-term care expenditures? Are they defined by law, are there any financial incentives etc.? Which government level (central/regional/local) uses the cost control instruments?
- Are fixed prices set by the central or local government (price settlement)?
- Is provision of informal care taken into account in needs assessments?
- How is needs assessment organized? Is the organization of needs assessment done by a government office or a private/semi-public institution?
- Is it possible that a person needs to go to two needs assessment organizations (local/regional) for different parts of his/her care? If so, how do these organizations then cooperate?
- Is there a highest level of services/health care you can be entitled to?
- Is there a limitation to the compensation which an individual person can receive (on his entitlement)?
- Is there any form of compensation possible for high expenses or user fees concerning care? If people are not able to pay their rent in e.g. an adapted home, their transportation services, meals on wheels etc., is there a social assistance benefit that can support the individual?

## Informal care

- Is there support for informal carers / family care in the form of a (paid/unpaid) care leave policy/legislation? How long, how often?
- Is there a difference between family care and volunteers in the form of (paid/unpaid) or care leave?
- What other ways of support are there for informal carers:
- Respite/relief services?
- Allowances?
- Tax deduction?
- Training?
- Are these organized and or subsidized (=paid for) by the government (central/regional/local)?
   Can you tell us something more about this subject?
- Is there a minimum level of informal care that people have to deliver before they can make use of any of the above mentioned support services?

# **Appendix 3** List of Interviewed People

**All countries** 

Annemiek Goris National Institute for Care and Welfare, Utrecht
Kieke Okma Ministry of Health, Welfare and Sports, The Hague

**Denmark** 

Christina Pederson Socialministeriet, Copenhagen

Sweden

Jonas Nilsson Social Insurance Division Sweden, Stockholm

Nina Petersen Swedish Trade Counsil, The Hague
Pernilla Kolni Swedish Trade Counsil, The Hague
Robert Carlsson Swedish Trade Counsil, The Hague
Masih Yazdi Swedish Trade Counsil, The Hague

Germany

Dhr. Pompe Bundesministerium Gesundheit, Berlin

**England** 

Raphael Wittenberg Department of Health, London

# **Appendix 4** Division of Tasks and Personal Reflection

## **Division of Tasks**

The study consisted of different steps. While the study was performed by two authors this appendix will present the division of tasks between the authors. Although all steps are performed by both authors, the contribution of the different authors somewhat differed from step to step.

Table A.3.1; Division of Tasks

Step	Anja Jonkers	Nicole Troisfontaine
Problem definition and deriving	+	+
research questions		
Research strategy and plan	+	+
Research framework development	+/-	+
Literature study	+	+
Formulate questionnaire	+	+
Interviewing	+	-
Data processing	+	+/-
Data analysis	+	+
Writing report	+	+
Finishing Touch	+/-	+
Briefing	+	+

While we considered the assignment as complex there was a need for a lot of communication about the scope, the approach and delineation of the assignment. Therefore most steps are performed by both of the authors. While the authors work for the same organization it was relatively easy to work together. In the literature study and data processing tasks were more or less divided, based on the different countries, but whereas the analysis is involved it was performed together, just to make sure the data was interpreted in the 'right' way.

The interviews were performed by only one of the authors to reduce the risk of different questions. The results of the interviews were subsequently discussed by both authors.

#### Reflection

It was clear in our cooperation that Nicole has more competence in thinking in systems and Anja is more familiar with the content of long-term care and social support. This made the cooperation fruitful (although Anja is very allergic to fruit) and we both learned from the skills of the other. There also was a difference in how far the authors looked ahead. Nicole reasoned backwards from the conclusions (even though we did not know where to get), while Anja had a more pragmatic view to keep the speed up.

Evaluating our thesis trajectory we both conclude that we learned a lot about performing an international comparison; the steps to be taken, but above all the need for similar concepts with clear and concise definitions otherwise you will not be able to draw meaningful conclusions. We very much enjoyed this trajectory although it did cost us a lot of time and effort.