

### **Social exclusion and care for the elderly: theoretical concepts and changing realities in European welfare states**

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**Social Exclusion and Care for the Elderly**  
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in European Welfare States

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## *Zusammenfassung*

Im Zentrum des Discussion Papers steht die Frage nach adäquaten Ansätzen in der Altenbetreuung zur Verhinderung von sozialer Marginalisierung älterer Menschen. Konzeptionell wird auf Ansätze der international vergleichenden Wohlfahrtsstaatsforschung zur Debatte um soziale Ausgrenzung („social exclusion“) zurückgegriffen, die auf die beiden Bereiche „Altern“ und „Betreuung älterer Menschen“ zugespitzt werden. Die Analyse sozialer Ausgrenzung erfordert eine Definition des Alterns-Prozesses, der neben genetischen insbesondere soziale, kulturelle und umweltbezogene Komponenten einschließt. Der Begriff „Inclusive Care“ benennt Charakteristika der Altenbetreuung, die es ermöglichen, Prozessen sozialer Ausgrenzung im Alter entgegenzuwirken.

Seit den 1990er Jahren wurden in den meisten Mitgliedsländern der Europäischen Union die Ansätze in der Altenbetreuung restrukturiert. Vor dem Hintergrund der Definition der Charakteristika von „Inclusive Care“ werden Finanzierung, Zugangskriterien, Diversifikation und Integration von Dienstleistungen sowie die Verbindung zur informellen Pflege untersucht. Dabei erweisen sich ein universeller Zugang zu Dienstleistungen verbunden mit sozialen Rechten, ein ausdifferenziertes aber integriertes Versorgungssystem, ein soziales Modell der Versorgung und die Anerkennung, Unterstützung sowie die Kooperation mit informell Pflegenden als entscheidend. Die Ergebnisse zeigen aber auch die Schwierigkeiten in unterschiedlichen europäischen Ländern auf, die Anforderungen zu erfüllen. Deutlich werden zudem Ungleichheiten zwischen verschiedenen Gruppen älterer Menschen, die in unterschiedlicher Art und Weise und Ausmaß von dem Risiko sozialer Ausgrenzung bedroht sind.

## *Abstract*

How approaches in elderly care should be structured to counteract processes of social marginalisation in old age is in the focus of this discussion paper. On a theoretical basis the paper draws on concepts of social exclusion developed in international comparative welfare state research. For the analysis of processes of social exclusion in old age, the ageing process is defined on a wide basis ranging from genetic, social, cultural to environmental components. The term “inclusive care” describes characteristics of approaches in elderly care, which enable processes of social exclusion to be counteracted.

Approaches in elderly care have been re-structured in most member countries of the European Union since the beginning of the 1990s. With the background of the defined characteristics of “inclusive care” modes of financing, access criteria and procedures, diversification and integration of service facilities and offers as well as the combination with informal care are investigated. The characteristics decisive for inclusive care are defined such as universal accessibility related to social rights, a diversified and integrated care system, a social model of care delivery and the acknowledgement, support and cooperation with informal carers. The findings prove the difficulties and obstacles encountered by certain EU-member countries to fulfil the criteria. Furthermore, according to their risk of experiencing processes of social exclusion, inequalities among different groups of elderly people have become apparent..



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## 1. Introduction: Social Exclusion and Inclusive Care <sup>1</sup>

The concept of social exclusion has increasingly gained significance in the scientific and political debate in Europe as a tool to analyse exclusionary processes in society. It aims at investigating the life situations of people at the fringes of society and thus extending the well-established concepts of poverty and social inequality. Research guided by the concept began within the area of unemployment and was only recently transferred to the issues of social exclusion in old age and the capacity of elderly care to prevent or counteract exclusionary processes. Both, the issues of social exclusion in old age and the definition of adequate elderly care, are at the centre of the discussion paper.

Initially, the origins, elements and definitions of the concept of social exclusion are presented. Despite a common definition of some basic features – like multidimensionality, relational or process orientation – social exclusion has proved to be still an elusive concept. In addition, the analytical potential of the concept within the area of elderly care is discussed. As a prerequisite dimensions of the ageing process are worked out which enable an analysis of the causal factors and processes of social exclusion in old age and the development of the decisive components of inclusive care, i.e. care which prevents or counteracts processes of social exclusion. The components of inclusive care apply to questions of access to different types of care services and the quality dimensions of services, like diversity of offers and integration, choice and control as well as integration and support of informal care. The definition of inclusive care forms the background for an evaluation of European approaches in elderly care.

The analysis of the different European approaches in elderly care is organised into different sections. The scientific debate on social care models gives an overview of the basic differences and decisive features of the care approaches. They are exemplified in the analysis as the modes of funding and types of benefits, the eligibility criteria and assessment procedures, the organisation of services and the role of, and support for informal carers (see section 3.1).

Since the 1990s in most western European countries approaches in elderly care have undergone considerable restructuring processes. The newly restructured approaches are

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<sup>1</sup> The literature review was made within the framework of the EU-project “Care For The Aged At Risk



assessed in respect to their strengths and weaknesses to promote the social integration of elderly people. In central Europe, especially, new modes of funding and types of benefits have been introduced. In addition, the eligibility criteria have been re-defined and corresponding assessment procedures have been established. Both, modes of funding as well as eligibility criteria and assessment procedures, determine the accessibility of different service offers (see sections 3.2 and 3.3). Services and service delivery were a further major subject of policy reform which aimed at building up a comprehensive care offer. Diversification of service facilities and offers, the integration of different types of care services as well as acknowledgement and support of informal care are the catch words describing the development (see sections 3.3; 3.4; 3.5 and 3.6). The results of the reform efforts have brought about new opportunities and impediments for different groups of elderly people. In the conclusion, the individual care approaches and their modification are evaluated in their capacity to enhance social integration. In addition, the risks of social exclusion that ensue for different groups of care-dependent elderly people and their informal carers are discussed (see section 4.).

## 2. The Concept of Social Exclusion

### 2.1 Origin and Basic Assumptions

Since the mid 1970s, increasing signs of political and social crisis have emerged due to restructuring in the capitalist mode of production, resulting in changing patterns of employment and, consequently, new challenges for the definition of the eligibility criteria for social rights (see e.g. Silver 1994; Jordan 1996; Littlewood/Herkommer 1999; Leisering 2000; Böhnke 2001). The European model for social inclusion via labour market participation and the corresponding access to social rights seems to be in a crisis. The ongoing process of social exclusion is viewed as a risk not only for the persons concerned but also for society at large. The political and scientific concepts of social exclusion were developed as a tool to analyse new forms of social cleavages and thus define new forms of research strategies for this social phenomenon and the scientific concepts of social inequality and poverty. With the concept of social exclusion, the issue of inequality between the top and the bottom spheres was extended to include the situation of members at the fringes of a society. The

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Of Marginalization (CARMA)”. Funding from the European Commission is gratefully acknowledged.

interrelationship of the three concepts – poverty, social inequality, social exclusion - is discussed controversially and ranges from the idea, that the concepts should complement each other to the idea that the concept of social exclusion should replace the concepts of social inequality and poverty (see e.g. Gray 2000; Lister 2000, Sen 2000).

Although at the beginning of the debate the concept of social exclusion was closely connected to problems of unemployment and poverty in society, it is gradually being applied to a wider range of areas. Kronauer (1997), for example, listed different dimensions of the multidimensional concept as:

- economic exclusion, e.g. labour market participation, adequate standard of living
- institutional exclusion, e.g. access to public institutions
- cultural exclusion, e.g. expectations towards certain groups in a society
- social exclusion, e.g. lack of social relationships
- spatial exclusion, e.g. local segregation living area

The multiplicity of the concept pertains to its cumulative nature. Social exclusion is viewed as a continuum of combined and accumulated disadvantages, which emerge gradually in a process of reduced social participation. The term ‘marginalisation’ was coined to define this gradual process and is defined as the process of becoming detached from the organisation and the communities of which a society is composed and from the rights and obligations that it embodies. Marginalisation focuses on relational issues, such as inadequate social participation, the lack of social integration and the lack of power. Thus, it is closely connected to a denied access to the principal social areas and on the basis of this, to processes of multidimensional and cumulative disadvantage. The described patterns of multidimensional disadvantages enable the identification of vulnerable groups in a society (Room 1995).

The assumption of the multiple and cumulative nature of the concept raises the question of how the dimensions reinforce each other. Whelan and Whelan (1995) describe this as the “need for conceptual clarity”. From their perspective, simply identifying dimensions of social exclusion does not allow a decision on their significance and their interplay. “If the identification of distinct dimensions of exclusion is to be fruitful we must direct our attention to the somewhat different factors that are involved in producing different types of deprivation and consider the variable consequences of specific types of exclusion” (Whelan/Whelan 1995: 37). In their view, distinguishing between determinants and outcomes seems to be

fundamental “to understand the dynamics of social change and processes by which certain social groups are excluded” (Whelan/Whelan 1995:37). In consequence, the systematic analysis enables the identification of the (cumulative) factors that trigger an entry to and an exit from situations of social exclusion.

The situational dynamic of processes of social exclusion is in the focus of the analysis of Wessels and Medierna (2002). According to their approach, it is within situations that the dynamics of exclusion materialise themselves and the actors encounter problems, analyse their situation and develop action strategies. Agency, ability and competence of the actors, the domain of exclusion and the available resource structures form the framework of action. They emphasise a positive self-concept based on notions of belonging, trust and access to relevant resource structures as a prerequisite for the development of successful action strategies. If one of these notions is lacking, effective action-strategies are impeded and processes of social exclusion can ensue. In consequence they demand “that the consideration of social exclusion needs to address the nature and processes of belonging, trust and accessibility of the resource structures” (Wessels/Medierna 2002:62).

They analyse the notions of belonging, trust and accessibility of resources on three levels, on a micro-level, i.e. in the individual biography, on a meso-level, i.e. in close environments such as neighbourhoods, networks etc., and on the macro-, the societal level. The positive function of belonging refers to integration and participation on the three levels, while in contrast a lack of belonging refers to societal fragmentation, social disorganisation and feelings of loneliness. Reliance on a government as well as expectation of a fair treatment characterise the positive functions of trust, while a lack of trust or mistrust appears towards authorities or institutions as well as towards others in the social environment. Finally, the positive functions of accessibility of resources lie in the opportunities to mobilise power and resources for social empowerment as well as resources for personal development and social participation. A lack of access is characterised by an increase in dichotomies between different groups in society, a low quality infrastructure and obstacles for personal development in individual life courses. Wessels and Medierna (2002) stress the interrelationship but also a kind of semi- autonomy of the development on the three levels. Especially, the societal level creates the framework for the development on the meso- and micro-level.

For Silver (1994), the definition of the causes of social exclusion and in consequence, the approaches and measures to prevent or counteract social exclusion are revealed to be determined by the prevailing political culture. Her threefold typology of social exclusion “solidarity”, “specialisation” and “monopoly” is based on different theoretical perspectives, political ideologies and national discourses. In the course of her article, she also distinguishes a fourth type, “the organic paradigm”.

According to Silver (1994), social exclusion is viewed in the French Republican tradition in the context of solidarity within a society, thus marking the dissolution of the social bond between an individual and the society in which he lives. “Insertion”, i.e. efforts towards social and cultural integration into a society, is viewed as the opposite process. Within the Anglo-American market orientated liberalism, social exclusion reflects discrimination, market failure and non-enforced human rights. In this paradigm, market competition and state protection of individual human rights impede social exclusion. Within the third paradigm, exclusion is seen as a consequence of group monopoly. “In this social democratic or conflict theory, exclusion arises from the interplay of class, status and political power and serves the interest of the included (...) The excluded are therefore simultaneously outsiders and dominated” (Silver 1994:543). Policies of full employment and the extension of social and civil rights are applied here as effective strategies to counteract exclusion.

With the organic approach of integration and exclusion, Silver (1994) develops a fourth perspective. The approach is characterised by the retention of a social order based on the different formations of social groups. The privileged position of the members of some groups results in the exclusion and disadvantage of the members of the other groups. The process of inclusion and exclusion is strongly supported by the state. On an ideological level, the principles of a harmonious society, embedded in the idea of subsidiarity, are emphasised and in contrast, class conflict is denied. Silver (1994) describes the paradigms as ideal types, which cannot directly be assigned to one society or one welfare state model.

The development of different assumptions for the causes of social exclusion enables a discussion on the societal responsibility for the processes of social exclusion, which is often neglected within the debate due to the focus on the individual (see, e.g. Byrne 2000). Silver`s (1994) paradigms reveal the relationship between different political cultures and the definition of causes on a societal level, while Wessels and Medierna (2002) focus on the situation and

the individual actors to reveal the dynamics of processes of social exclusion. The notion of social exclusion is nevertheless used in both approaches in a broad perspective regarding “the processes of social exclusion in a society, respectively in situations”. The use of the concept in the scientific debate on the elderly and care systems uncovers the conceptual power of this hypothesis in a more limited and defined area.

## 2.2 Social Exclusion and Elderly Care

The basic concepts of social exclusion and marginalisation have only recently been transferred to the research area of social care, in particular, the care of the elderly. How the concept of social exclusion can be connected to the concept of equity, fairness, typically used for evaluating service provision, is considered a key conceptual issue. Österle’s approach (1999, 2002) establishes a starting-point for this transfer by defining four sets of equity objectives specifying the hypothesis of a “fair distribution of resources in a society”. He distinguishes between three quantitative dimensions; the first is “guaranteeing minimum standards”, the second, “supporting living standards” and the third, “reducing inequality” and a fourth qualitative dimension of “promoting social integration”. The third dimension relates the situation of the individual to the average situation in a society. On the basis of this, he demands that not only vertical re-distributional efforts be made to counteract inequality between rich and poor but also horizontal efforts, i.e. pertaining to the family status within a society. The fourth dimension of equity, “promoting social integration”, necessitates the reduction or prevention of processes of social exclusion. It includes issues of social rights, social and individual responsibilities, solidarity and autonomy. Österle (1999, 2002) claims that the qualitative dimension of social integration is strongly related to the quantitative, i.e. that the allocation of resources has a significant impact on the key dimensions of social integration and participation. The assumption is supported by the approach of Wessels and Medierna (2002), who regard accessibility of resources as a basis for social empowerment and individual development. Both, social empowerment and individual development are defined as a prerequisite to counteract or prevent processes of social exclusion. In his theoretical approach, Österle (1999, 2002) concentrates on the three quantitative dimensions of equity, putting forward the difficulties of empirically defined measurable dimensions of the concept of social exclusion in social policy.

In accordance with Österle(1999, 2002), Blackman et al (2001) compare the wider concept of social exclusion with what they see as the narrow concept of equity, which covers operational questions and the issue of service allocation. In contrast to Österle (1999, 2002), however, they focus on the concept of social exclusion in their approach and use this concept instead of equity to evaluate care services. Their research is aimed at defining the characteristics of inclusive services, i.e. the services, which prevent or counteract processes of social exclusion for the elderly (Blackman et al 2001). As starting-point for their analysis, they refer to the ideas of solidarity, citizenship status and participation in a society as the key features in the debate on social exclusion and marginalisation. They define social exclusion (of the aged) as the denial of citizenship rights, the lack of participation and integration into social life as well as a lack of autonomy and as the corresponding status of dependency. These notions have to be adapted and put into concrete terms by analysing the ageing process and the corresponding field of care for the aged.

Blackman et al (2001) view the ageing process as the interaction of genetic, environmental and social factors. Hence, in their definition of social exclusion processes in old age, they combine a broad range of dimensions, which is, in consequence, a complex, yet still elusive concept of social exclusion. The complex nature of their definition allows a reevaluation of the interplay of the different dimensions, their relationship to social care policies and the organisation in a broader societal framework. In their view, ageing is accompanied by the risk of enduring difficulties, such as physical disabilities or psychological disorders like depression, the risk of loss of affective relationships on the social level and the risk of economic constraints due to inadequate old-age pensions. Old age is further socially constructed and characterized by cultural expectations and attitudes towards the elderly that exercise a powerful influence on the quality of life of elderly people.

The findings of the European project “OASIS” confirm the broad approach for an analysis of the ageing process and its relation to the issue of social exclusion. The researchers emphasise the economic situation, the educational background and the health status as decisive for the degree of autonomy in old age and the delay of dependency (Tesch-Römer et al 2003). The Berlin Aging Study has proved that the health status is decisive for the performance of daily functions (Baltes/ Mayer1999). The maintenance of these functions form a precondition for the involvement in social or leisure activities, whereas the participation in such activities is determined further by the status and income mediated by personality and cognitive

competences. Both the performance of daily functions and the participation in leisure and social activities are seen as two basic elements of a “successful ageing process” (Baltes/Mayer1999). Strong networks of families, friends and neighbours are regarded as vital for older people and have been revealed to be a significant source of social integration, especially for elderly people living in areas characterised by social deprivation (Scharf et al. 2001). Both social relations and social activities themselves also correlate positively with the health related quality of life (George 2001).

Life situations, which support the development of successful ageing, depend on how basic needs of the elderly are met, e. g. nutrition, housing, social support, etc., all of which are strongly connected to social class or gender (SVR 2000/2001; Baltes/Mayer 1999; Kruse 2002). Changes inherent to the ageing process affect the elderly, in consequence, not only at different rates and in different ways, but according to the degree of vulnerability of the elderly themselves and the coping resources and styles available to them. The different effects determine whether the changes may or may not result in a loss of autonomy, independence and quality of life for an elderly person.

Blackman et al. (2001) emphasise that the extent to which a person can fall back on the resources needed depends not only on the material or social dimensions, but also reveals an ideological aspect reflecting cultural expectations in relation to elderly people within a society. From the authors’ perspective, social exclusion occurs when an old person cannot control the needed resources to meet the demands of an everyday life of autonomy that most other people would take for granted. Blackman et al (2001:162):”Social exclusion exists because access to a resource – including both material and social resources – is prevented by economic, political and social barriers. The barriers are constructed by a mechanism of exclusion controlled by people with more power than those who are excluded. Exclusion for some is created by the actions, words and beliefs of others, and although economic power is a key factor, exclusion is also created ideologically through the social construction of marginality and vulnerability in both political and everyday discourses”. Within the debate on ageism, cultural obstacles are viewed as emerging due to a set of beliefs on the biological variations between people according to their chronological age. Ageism generates stereotypes regarding competence and the need for protection, which can be used to systematically deny resources and opportunities that others enjoy (Bytheway 1995).

The absence of rights, marginalisation in economic and political power, as well as isolation from the mainstream of society tend to compound each other in the most vulnerable older people. The underlying concept of social exclusion stresses the idea of cumulative, mutual reinforcing dimensions. Furthermore, social exclusion cannot be defined as a static outcome. The focus of the analysis must be on the “exclusion mechanism”, the structures and processes in a society, which marginalise old people and their needs within a given welfare culture. Social exclusion is about structures and processes that deny resources to some groups of elderly people in the interests of more powerful groups in a society and on the individual level about how elderly people actually feel and act. Thus, the objective and subjective dimensions of control must be taken into consideration in the analysis of processes of social exclusion and their significance for different groups in a society (Eriksson 1974, Schwarzer/Born 1995; Tesch-Römer et al 2003). Objective control, which is defined as having the power to control significant resources, constitutes only one prerequisite in the exercise of control. The actual exercise of control is additionally influenced by individuals’ beliefs in their own capacity to control environmental factors. The necessity to combine subjective and objective factors is confirmed by the approach of Wessels and Medierna (2002). According to Wessels and Medierna in situations at risk of marginalization actors do not only draw on resources provided by the society or by social networks within the neighbourhood respectively social networks, but, on an individual level, may also use life-course experiences as a psychological resource structure.

The exercise or lack of power and control are defined as key issues in Gibson’s (1998) analysis of the situation of care-dependent elderly. Initially, she questions the significance of the dominant objective of current old age policy - the promotion of autonomy and prevention of dependency - when the target group under consideration is in fact (care) dependent. In response to this, she distinguishes different types and levels of dependency. Drawing on gerontological findings, she states that the acceptance of dependency in old age can represent a positive adaptation strategy when the individuals remain independent in key areas of their lives (Baltes 1988; Baltes/Silverberg 1994).

In accordance with the findings, Gibson (1998) queries the dimensions of dependency that contribute to a negative assessment of dependency, when dependency as such cannot be avoided. She names the lack of power and control as negative dimensions of dependency, which she terms “negative dependency”. This can develop on a micro level as a part of a care



relationship and can be closely linked to the organisation of care processes. The micro and meso perspective must be extended to the macro level to enable an analysis of socially constructed forms of dependency. On the micro-level, negative dependency ensues from the so-called “overcare”, i.e. care, which is given in areas where the care-dependent person could manage without assistance. This phenomenon exists when the capacity of the individual to make decisions is reduced (Baltes 1988; Baltes/Silverberg 1994) and is often found in institutional settings (Jack 1998). Negative dependency constructed on a societal level is linked to societal rules. Society may cause and strengthen this by direct means, e.g. the exclusion from the labour market by mandatory retirement or by indirect means in the exclusion from various social responsibilities and activities by social attitudes towards what is or is not appropriate for elderly people.

As a result of her analysis, Gibson (1998) claims the enhancement of the access to power or control on the micro, meso and macro levels as the central challenge towards the avoidance of negative dependency. She defines the criteria, which determine the degree of powerlessness an individual is likely to experience, in specific care dependency relations. From her point of view, the asymmetry of dependency and the lack of mutuality lead to the potential of exploitation. She develops three criteria to define the extent of negative dependency in a given situation:

- the extent to which the dependent individual needs the required services
- the availability of alternative resources and
- the level of discretion of the resource holder in providing the required assistance

The access to resources, the availability of alternatives, the power of decision-making and a broad definition of the ageing process, including genetic, environmental and social factors have been revealed to be significant variables that must be considered in the analysis of the interaction between social exclusion, the elderly and the care services. These findings place demands on the allocation of care services, i.e. on the definition of the eligibility criteria as well as on the assessment and allocation processes. Different living situations and unequal access to resources for certain groups of elderly people necessitate a closer look at the different perspectives of equity. A choice between different (types of) services does not only apply to the question of their availability but to their affordability and accessibility. Care services provide only one part of the necessary care. The bulk of care for the elderly is carried out by informal carers within the family framework. The support of informal carers and the

integration of informal care into formal care services often form the prerequisite for the realisation of different alternatives.

Besides the issue of access to different types of care (services), the findings clarify quality demands on care provision. Both, the variables of objective and subjective control and decision-making, pertain to the care process, while the broad view on the ageing process necessitates the establishment of a comprehensive care offer, including health and social care as well as prevention measures to limit the degree of care dependency. How the care systems, i.e. care services and informal care, respond to the demands, where the obstacles emerge, which groups of elderly are at a disadvantage and whether and how this might effect the processes of social exclusion will be analysed in the following chapters.

### 3. Care Systems: Dimensions and Modifications in Elderly Care

#### 3.1 Welfare Mix: Models and Components

Due to the rising average life expectancy and declining birth rates, the present demographic situation in European countries is characterised by an increase in the number of elderly people and their percentage of the total population. During the 1990s, expectations on corresponding care needs, changes in family structures, new-definitions of political ideologies and economic restraints gave impetus to restructuring processes in elderly care as well as to international comparative research on the issue of social care for the elderly (see e.g. Jamieson 1991; Alber 1995; Giarchi 1996; Tester 1996; Hutten/Kerkstra 1996; OECD 1996; Walker/Maltby 1997; Glendinning 1998; Lewis 1998). Research findings have revealed that the basic components of care for the elderly are similar within the EU, but they vary considerably in their significance in reflecting each country's care policies and its structures. The levels of social provision for elderly people do not tend to harmonise within the member states of the European Union (Tester, 1996; Pacolet et al 1994, 2000, Anheier 2000).

Inspired by Esping-Andersen's (1990) approach on welfare state regimes and feminist criticism during the 1990s, which emphasise the neglect of social care as an important area of gender-sensitive research, social care models were developed to construct new models on the basis of fundamental features. In the initial construction of social care models, Anttonen and Sipilä (1996) defined social services as a universal service available to all citizens, which is

controlled and subsidised by state authorities. Drawing on the approach of Orloff (1993) who replaced Esping-Andersen's concept of "decommodification" with that of "personal autonomy", they highlight both the independence of the market and the family as vital from a gender perspective. On the basis of the criteria of the "way of organising" and the "volume of social care services", Anttonen and Sipilä (1996) distinguish three social care models. The Scandinavian model is characterised by its universal character and the wide availability of (public) social services with the middle class among the users of public services. Local governments play a key role in organising and funding the services. Characteristic of the social care approach in the United Kingdom, as in the Scandinavian model, is the responsibility of the state for the provision of social services, but in the United Kingdom, means-testing ensures that the services are allocated to less wealthy people. Citizens who can take on the economic responsibility themselves are expected to provide for their own services.

Anttonen and Sipilä (1996) compare this state responsibility model with the family care model, which is represented by Portugal, Spain, Greece and Italy. In these countries the family is the main provider of social care. The supply of social services is restricted to a modest role of state authorities. In consequence, the informal and grey market produces most of the services. Wealthier people use the privately paid commercial services. Finally, they define the central European subsidiary model, represented by the Netherlands, Germany, Belgium and France as the third model, where the family takes on the primary responsibility for the care of the elderly. Religious and political organisations are the major producers of services and substitutes, which replace informal family care when necessary.

In contrast, the welfare mix approaches of Evers and his colleagues proceed on the assumption that the different areas or actors of care provision are evident in all European countries (Evers/Wintersberger 1990; Evers/Svetlik 1993). The countries have established their own mixed systems of care, which differ according to the significance and scope of areas, their organisation and funding. The approach was created to show the significance and interplay of different actors, i.e. the public, market, voluntary and informal family involved in providing social care. Each of the different areas is assessed as useful but imperfect and in consequence, the involvement of different actors in social care provision will result in a synergetic effect. The assessment of the consequences of the shift towards the market and the voluntary sector, however, is seen to necessitate research on the changing quality of social welfare and the well-being of individuals.

In their efforts to restore the welfare mix approach, Sipilä and Anttonen (1999) analyse the different modes of producing social care and their consequences for care givers and care receivers in regard to the issue of social and gender inequality. As a starting point, they chose the relationship between carers and care receivers, which becomes more complicated when it becomes formal due to the increasing number of actors. The modes of producing care, i.e. voluntary, commercial, grey market, public or by the families differ in regard to the financier, the mode of financing, the producing unit and the resulting consequences for carers and care receivers. In their findings, they describe the typical users of different types, showing that the modes of producing care are strongly linked to class position, citizenship status or family status. Furthermore, the working-situation of the carers differs according to the cash payment received or to the working conditions. Like Sipilä and Anttonen (1999), Stark and Regner (2002) analyse different modes of care provision and their consequences for the carers and care receivers. In order to reveal the consequences of the different approaches, they include even assessment procedures and access criteria to societal support as well as the preferences and desires of the elderly according to the provision and the funding of care services.

In their analysis of social care approaches in western European countries Knijn and Kremer (1997) view welfare state regulations, especially established citizenship rights, as decisive for differences between the countries. In the focus of their analysis is the question, whether and how the two fundamental rights “the right to time for care and the right to receive care” have become regulated and accepted as citizenship rights. The right to time for care includes regulations concerning care leaves, e.g. parental leaves, paid terminally ill allowance or different types of payment for care and the opportunity to combine work and care. From the perspective of the care receivers different ways to define access to care are prevalent. Despite similar objectives in elderly care in the compared countries – to enable the elderly to stay in their homes as long as possible -, both, the amount of care given through the welfare state and the mix of care still differ substantially. As a result in some welfare states elderly people are largely dependent on the sense of moral obligation of their family members, while other welfare states grant the right to receive care to the elderly.

In accordance with Knijn and Kremer (1997) Daly (2000; 2002) regards the provision of social care services as only one type of societal support among others. She includes as further areas of societal support the provision of time for care and different types of financial support. She defines four different types of measures, which have been introduced in welfare states.

The first type of measures concerns different forms of monetary benefits, e.g. cash payments, the second type applies to employment-related provision, e.g. paid and unpaid leaves, the third type concerns public services and finally the fourth one describes incentives towards employment creation in the market, e.g. through vouchers.

By distinguishing between the variables time, money and services Francesco and Plantenga (2003) outline a three cluster social care approach. They construct an “all in the family cluster”, in which care activities and the management of care are delegated to the family. In this model, represented by Greece, Italy and Spain, the support of the caring family with financial provision, services and time, i.e. different leave arrangements, such as parental leave, the actual reduction of working time for carrying out care activities is low. In the second cluster, “the public financing of private care cluster”, a largely informal, family-based care strategy is predominant. In this model, however, publicly provided financial provision and different types of leave facilities support the care giving family, while the provision with services is rather low. Germany and Austria are assigned to this model. In the third cluster, “the public care cluster”, with its representatives, Denmark, Finland and Sweden, informal family care plays merely a modest role. The families are supported by a wide range of universally available services but also by generously funded leave facilities.

The development of different social care models since the 1990s reveals the complexity of social care approaches and the variety of dimensions which have to be considered. In their approach Daly and Lewis (1998, 2000) define three basic dimensions of the concept “social care”, in which changes of social care delivery may occur. The goal of this approach is to deliver a framework for the analysis of changes of social care approaches. They define social care as a multifaceted concept with three basic dimensions located on a micro- and macro level. The first dimension emphasises care as labour. This perspective of care as an activity enables an investigation into the nature and conditions of care work and how they are related to the welfare state. The second dimension views care within a normative framework of obligations and responsibilities. Here, the focus is on the social relationship in caring activities, the issue of social and/or family responsibilities and the influence of the state in the development of care activities within the family framework. Finally, the third dimension emphasises the sharing of financial and emotional costs of the care activity. Costs are shared on a macro and micro level and extend across private and public boundaries.

Like Daly and Lewis (1998, 2000), Anttonen et al. (2003) built up a framework for the analysis of the development of basic dimensions in social care delivery. In contrast to the dimensions used by Daly and Lewis (1998, 2000), Anttonen et al (2003) define dimensions where a direction of the development can be observed. In the first, "Social care going public", they describe the increasing share of care activities, which have completely left the private domain of the household and are provided as formal services. The second and third dimensions describe changes in the allocation principles of services. In the second dimension, they located a process of individualisation, i.e. whether publicly funded social care services are allocated on the basis of family status or on the needs of the individual. Finally, in the third dimension, they analyse the process of the universalisation of social care moving from the selective form to becoming universally available (for greater detail see section 3.3.1 ). On the basis of their approach, Anttonen et al (2003) assign different types of care services in the countries compared in their research, to certain points in the three dimensions and thus describe their quality and analyse their development. As a result they can assess the quality of the services according to the different dimensions.

The social care models and their basic components outline significant dimensions for the analysis and comparison of social care provision. The dimensions have been extended since the beginning of the 1990s. While at the beginning they examined funding, care sectors, their interplay and their consequences for care users and carers, they are gradually including more components to analyse access to the services as well as further societal support for carers and care receivers. These developments reflect a change in social care delivery. Since the beginning of the 1990s social care approaches have been characterised by an increasing marketisation, i.e. a withdrawal of the state from service delivering, and corresponding efforts to establish fair access to the services for all citizens as well as an increasing recognition and support of informal family care.

The construction of the approaches reveals the basic differences between countries as well as the significant dimension for the analysis of social care provision. The findings of Blackman et al (2001) show that, in principle, different social care-models, the service-oriented model of the Northern countries but also the family model in Southern Europe can counteract or prevent social exclusion in old age. Decisive are the more detailed regulations in different areas of care provision, which may for some groups of elderly enhance the risk of social exclusion. Whether and to which extent different regulations concerning funding, access, type

of care provision and their integration as well as the recognition of informal care can counteract exclusionary processes is analysed in the following chapters.

### 3.2 Financing Long-term Care: Mode of Funding and Types of Benefits

Since the 1990s, the expected care gap in family care has prompted a change in the mode of financing to secure an appropriate care offer in long-term care. New modes of collective long-term care financing have been introduced, as well as new definitions for collective, individual and private economic responsibilities for different types of care. In addition to the funding of care services, a variety of cash benefits have been established to support informal family care. Throughout Western Europe, the main social policy activity of increasing collective funding of long-term care, is viewed as an indicator that long-term care has gradually acquired a more public character (Daly 2002)

#### 3.2.1 Modes of Funding and User Costs

In their analysis of the changing modes of collective funding of long-term care, Pacolet et. al. (2000) assigned the (western) European countries to two basic models – a Beveridge-orientated and a Bismarck-orientated model. The tax financed social and health care services of the Beveridge orientated countries have integrated their long-term care services into the existing health and social services. The researchers describe the form of funding as a more implicit long-term care insurance. In this model, they differentiate the United Kingdom's more moderate public funding of services from the Nordic countries, which have a higher level of publicly funded services. In the latter, where social care services were already well established at the beginning of the 1990s, the focus was more towards restructuring and even downsizing. In the course of this process, the former homogenous Nordic model of long-term care developed in different directions. While in Denmark home care coverage increased substantially, it remained stable in Norway but declined sharply in Sweden (Trydegard 2003). The decline in coverage in Sweden was not due to a reduction of funding, but to an insufficient increase in public resources for funding in accordance with the rising number of elderly people and the increasing demand for home-based care due to the restructuring process in the health care sector (Palme et al. 2002).

In the 1990s, there were marked signs of a so-called under-insurance in the welfare states orientated on the Bismarck model. They are summarised by Pacolet et al (2000) as;

- high levels of payments by the elderly themselves
- a recourse to family resources or social assistance
- underdeveloped long-term care services

In the Bismarck-orientated Mediterranean countries there was little debate on the subject of long-term care funding. They have retained their strong attachment to care provided within the family framework. In contrast to this, in the Bismarck-orientated central European countries, the issue of care has led to an intense debate on the introduction of new sources of funding for long-term care.

Separate, insurance- and/or tax-based, systems of long-term care funding were introduced in Austria, Germany, Luxembourg and on a provincial level in Flanders, Belgium (Eisen/Mager 1999; Pacolet et al 2000). Research findings in Belgium have revealed that the available services already cover the care demand to a certain degree and merely require limited additional financing (Pacolet et al 2000). In Flanders, the contributions for the newly-established long-term care insurance amounted to 25 € per annum in 2003. But the corresponding low level of benefits is compensated by highly subsidised social service provisions and income-related co-payments (Cuyvers/Peloton 2003).

In Germany, the higher long-term care insurance contributions (1.7% of gross earnings) reflect that additional funding must be regarded as inevitable and show in consequence the significance of the insurance for funding the care (services). Prior to its introduction in 1995/96, long-term care had to be provided within the family framework and paid for either by the elderly themselves or by their relatives. The costs of long-term care were covered by the health care insurance or by the welfare system after means-testing, but only under strict and limited conditions. Care dependency became a risk of impoverishment for the individual and a financial liability for the municipalities (Ostner 1998). This financial burden declined for municipalities as well as for individuals and their relatives on the introduction of the insurance. Since then, the number of home-based care providers has doubled, revealing the underdevelopment of the previous service offers. The comparatively high insurance benefits, which are granted in case of care-dependency are meant to pay unsubsidised market rates for formal services, which are not adapted to the income of the individual user.



In 1993 in Austria, a tax-based system of care allowance was established in co-operation with the federal government and the provinces. The care allowance ranges from 145 € to a maximum of over 1500 € but in 2002 more than half of all recipients were in the lowest allowance levels and received at most 268 € per month. The benefits can be used to buy formal care services or to pay for informal care. Formal care provision is subsidised, enabling the calculation of income related prices for the users. A full coverage with formal care services has only recently been attained in Austria (Egger de Campo/Just 2003)

Long-term care benefits are generally not limited to the elderly, they provide financial provision in clearly-defined care situations to dependants of all ages. The insurance very often covers only the basic expenses for a fairly wide range of areas, such as the costs for basic nursing care, housing and housekeeping. The benefits can be granted in the form of services or cash support for the recipient or the caregiver. Independent of the mode of financing, most countries distinguish between health care services and other types of long-term care or social services (see Pacolet et al 2000). The expenses for home based nursing care, for example, are defined in most European countries as a public liability and funded by an insurance or tax-based health care system. In contrast to this, the degree to which long-term care or social services are publicly funded varies widely according to the country and the type of service. In the Nordic countries, in Belgium and in The Netherlands more than 80% of the costs for social care services were publicly funded until the mid 1990s. In Sweden, the United Kingdom and Norway, users must contribute to the costs with income-related co-payments. In Germany and Austria, the insurance benefits cover home-based basic nursing care or social services but they must be supplemented by the beneficiaries themselves or through further social benefits (Egger de Campo/Just 2003; Theobald 2004).

In contrast to basic nursing services, household services are regarded in most countries as a private economic liability. Even in countries like Sweden with more generous public funding, public financing has been withdrawn from the household area. The decline in the number of receivers of municipal home help services is caused to a large extent by the reduction in the services pertaining to housekeeping. Due to an increase in user fees for minor household help, women with low pensions have withdrawn from using municipal services for financial reasons. (Szebehely 1999, 2000; Trydegard 2003). The cost of adapted housing or the adaptation of a person's own home to the needs of a care-dependent person as well as similar

types of social services are often subsidised by long-term care insurance benefits or by tax-based welfare state benefits.

Residential care services are publicly funded in all member states of the European Union, with the exemption of Ireland (Pacolet et al 2000). However in most cases, the public liability applies only to the necessary basic care provision and to a lesser extent to the mainly privately determined hotel costs. In 2001 in Germany, an average of 71 to 80% of the nursing rates in residential care homes were covered by the long-term care insurance, but hotel costs and even the costs for investments in the residential homes had to be paid for by the care receiver depending on the level of subsidisation from the individual federal state (Theobald 2004). The costs for old people's homes are publicly financed to a higher degree only in The Netherlands and in Nordic countries. The pattern reflects that services more closely related to basic and nursing care needs are more often defined as public issues but the costs of further forms of institutional living to a much lesser degree.

### 3.2.2 Cash Benefits and Informal Care

The new definition of public liability for financing care services since the 1990s corresponds to the increasing share of cash benefits as opposed to services. Daly and Lewis (2000) describe the new balance between cash transfers and services as a major trend in the area of social care, where the mixture differs between and within welfare states. "It involves not just the old either/or constellation of service, cash transfer or taxation but rather differentiation in the manner in which cash and services are combined to support private or public care on the part of the welfare states "(Daly/Lewis 2000:292) As a result, the boundary between formal care (provided by public, voluntary or commercial organisations) and informal care ( by family members, relatives, friends or neighbours) has become an area of conflict, re-negotiation and newly-developed forms of co-operation. The shift from service provision to cash benefits is justified with the promotion of more choice for the service users, an acknowledgement of informal care provision (carried out mainly by women) and the goal of cost-efficiency, i.e. with the aim of lowering costs (Daly/Lewis 1998; Ungerson 1997).

The introduction of different types of cash benefits began during the 1980s with payments for the informal care giver. Ungerson (2000) distinguishes care allowances of different sizes and

purposes from proper wages. The care allowance, as in the British Invalid Care Allowance, the American Federal Dependent Tax Care Credit and the provisions of the Danish Social Assistance Act, is meant as a supplement for earnings forgone, for people in paid employment, while the Irish Caregiver's Allowance is for carers of all ages who give up paid work to look after a care-dependent person. The amounts paid vary from country to country and range from coming close to proper wages in the US and barely at subsistence level in Ireland. In the Nordic countries, for example, the allowance paid to the informal carer is almost equal to the wage the care giver could earn in paid formal care. Wage-orientated allowances are linked to a regular employment status and include social insurance, sick benefit, paid holidays and bereavement counselling. Hence, in countries with a minimum wage policy the costs of care can be very high.

During the 1990s, the newly established types of cash payments were mainly orientated towards care receivers and aimed at empowering them and giving them the possibility of choice. An increasing consumer awareness was meant to enable the care recipient to get the best quality of care at the lowest prices. The amount of the payments ranged from a symbolic amount to proper wages (Ungerson 2000). Payments of a symbolic character, i.e. defined as a form of acknowledgement for informal work but not as high as wages, allow the care receiver a reciprocal payment, which can be used to make a gift or to give cash to the informal carer. In Germany, for example, cash payments provided by the long-term care insurance are used to "pay", at least nominally, relatives or neighbours and to buy domestic services on the so-called grey market (Evers 1997). In some countries, e.g. Austria, Italy, France, Denmark or United Kingdom, the care receivers are given the means to employ caregivers directly in an employer/employee relationship. In Denmark and Austria, relatives, friends or neighbours can be employed by the care receiver.

Cash payment may, however, also encourage the provision of care in an informal setting with possible negative consequences. Questions arise on how well this type of measure tackles the difficult terrain between the mutual rights and obligations of informal and formal care. Informal care work has the tendency to leave the informal care givers quite isolated, because they are not usually integrated in a network. One negative consequence for the care givers could be that it prevents them from seeking gainful employment elsewhere. Furthermore, indications for an international division of caring and housekeeping work is found in research

on the situation of immigrant women who carry a heavy work-load in an often insecure and even illegal working-situation (Hochschild 2000; Hondagneu-Sotelo 2000)

There is very little research on the influence of this type of cash payment on the care relationship. Ungerson (2000) summarises the results of a study on the question of control and power in the care relationship. Employing friends or family members may lead to vulnerability on both sides. It is difficult to distinguish between paid work and unpaid support where paid carers feel obliged to work beyond the working contract. The empowerment of the care user, the right to hire and fire, leaves the care giver in a dependent situation. Ungerson (2000) states that the claims of empowerment of the care users and the recognition of informal care work are far too generalised and thus the effects of cash on caring relationships call for more intensive research.

With the introduction of long-term insurance, the changed modes of funding long-term care in central European countries, especially, has increased the opportunities for care-dependent elderly people to use services and has improved their economic situation. There is a common trend in western European countries towards financing needs that are closely related to health- or nursing care. In contrast, whether and to what extent costs of social services, hotel costs in residential homes or old aged homes or assistance with household chores are publicly funded differs widely between countries. In regard to different types of services, the Nordic countries and to some extent The Netherlands and Belgium appear to be the most generous countries, thus increasing the alternatives and choices from the perspective of the users.

The availability of “real choices” between different alternatives for the whole population can be viewed as one important step forward to provide people with adequate resources and thus prevent or counteract processes of social exclusion in case of care-dependency. Collective funding of different types of care can be regarded as one prerequisite for the availability of services for all groups of elderly. The differences of funding in regard to the various types of care provision, especially the neglect of social services in collective funding arrangements in most of the countries, impedes social participation for disadvantaged groups of elderly and thus increases the risk of marginalisation.

### 3.3 Accessibility: Allocation Principles, Social Rights and Assessment Procedures

Public funding of different types of care services determines the individual costs for the care users and thus the overall affordability of the services. However, whether an individual can use the publicly funded services or has access to different types of benefits is dependent on the eligibility criteria for the service allocation, assessment procedures and their realisation, which differ from country to country or according to the type of service.

#### 3.3.1 Allocation Principles in Care Delivery

Österle (1999, 2002) views equity or fairness as the guiding principle in the allocation of resources in social policy approaches. A definition of what is considered a "fair" allocation of services as well as a definition of the units, which evaluate the outcome of the established mechanisms is a prerequisite for the attainment of equity within the area of health and social care. But the final outcome cannot be linked directly to the allocation of care resources. Instead, the issues of use and access to services provide data which can be analysed from the perspective of equity.

In the area of health and social care, the patterns of service utilisation generally differ between the user groups. Comparable data on access, i.e. the eligibility-criteria, reflects the opportunities of service utilisation and can be used as a starting-point to reflect unequal utilisation patterns. In principle, the varied access to different services enables an analysis of an individual's freedom of choice with the different alternatives. However, within the health and social care sector, different patterns of service use are not necessarily based on a voluntary choice, despite equal eligibility criteria. The limitations on an individual's freedom of choice may occur for different reasons, such as a lack of presupposed resources or information and/or a lack of adaptability of the different services in an individual situation. Both the variables of access and use of services provide the necessary basic information on the adequacy of allocation principles and must be examined both independently and in regard to their interplay (Österle 1999, 2002).

The most popular allocation principle in social policy approaches, especially in the (health) care sector is the principle of "need". Equity could be defined here as "equal access and equal

use for equal needs, respectively, even when it is difficult to empirically demonstrate a link to an equal outcome". In the definition of needs a distinction must be made between subjective and objective needs. In health care, for example, an individual's subjective preference for a certain service or medical treatment and the actual intention to use the service, i.e. the subjective need, can be compared with a professional's confirmed "objective needs" (see SVR 2001:25). Professional decisions on objective needs can be based on scientific findings, which define the adequate treatment and measures for successful health care. Need-based allocation principles are usually combined with further principles, the most prominent of which are economy related principles. In a positive sense, economy related principles for the allocation of health care services are aimed at improving efficiency by selecting the most economic approach on an individual or group level, resulting in the same outcome. However, cost containment policies are at risk of withholding the necessary resources for clients and thus enhance health problems.

In most Western European countries, health care services are still mainly regarded as a public liability with the prevailing principle of universal access based on needs and the idea of cost efficiency. The high level of public funding within the area of health care can be viewed as an indicator for the assignment of this public responsibility (Pacolet et al 2000). In the case of long-term care or social services, the principles of service allocation are less dependent on scientific consideration. The principle of the acceptance of societal responsibility for different care situations and in consequence, the decision on public funding and/or public organisation or provision of services is decisive for service allocation. In their cross-country research, Anttonen et al (2003) describe two dimensions of development as the individualism and the universalism of service orientation, marking the starting point for the reflection of the allocation principles

Anttonen et al (2003) draw on the research of Hill (2000) who defines two basic criteria for care delivery. He distinguishes in the first dimension, whether services are allocated according to the principles of means-testing, universalistic or insurance based entitlements. The second dimension examines the alternatives of individualist and family responsibility assumptions. On the basis of this, a typology of six distinct regime types is exemplified where the different principles are mixed. From his point of view, counting the family side can be used as a justification for rationing services.

He describes different ways family assumptions can be made in relation to care policies (Hill 2000:215):

- “The extent to which assumptions about what families do affect the overall supply of services
- The use of assumptions about what families may do in situations in which rationing is needed
- The crafting of benefit rights in ways that assume family inputs”

The process of individualisation and universalisation is shown to be mixed in the countries compared by Anttonen et al (2003): Social care provision started out as assistance for older people, when a form of social obligation could not be assigned to family members. In a further step, the entitlement became increasingly family- or household based. The objective was to support care within the family framework and the household income using means-testing as the eligibility criteria. Social care entitlement that is entirely universal and based on individual needs can be viewed as the culmination of the two processes of individualisation and universalisation.

In most countries, the eligibility criteria do not develop in one direction. Many countries are developing both policies, i.e. policies that accord care entitlements to individuals and others that support or even enforce family or community obligations, including the establishment of different forms of income related or means-tested allocation principles. In Estonia, for example, even the income of the children and grandchildren is taken into account in the calculation of the required co-payments for the use of social services on the local level. The decision, whether and on what terms a person may receive services, is made on the local level. Because the co-payments are very often beyond the means of the family members, the elderly person does not receive any service (Saks et al 2003). In Italy, the income of family members is only taken into account when the elderly person lives with the family in the same household (Antomarini/Sdogati 2003).

Different types of care services can be universal in one country and selective and sharply rationed in another country, just as the allocation principle can vary between the different types of services within a country. The selective and family-orientated services are usually developed on the local level, while the service entitlement established on the national level are

orientated towards universal, citizenship rights. This can cause complex boundary problems and implies an inconsistency and inequality between the two systems for the users (Anttonen et al 2003).

The introduction of the long-term care insurance in central Europe during the 1990s also brought about a change in the allocation principles. In most countries, with the introduction of the insurances, (near) universal social rights were established on a national level with the corresponding allocation mechanisms orientated towards the needs of the potential care-dependent person. In Austria, care needs are assessed on the basis of the hours needed for assistance and support for a specific individual care-dependent person. The assignment of the different levels of required help determines the amount of payment, independent of whether the beneficiary will use informal assistance, formal care services or move into a residential home. In Flanders, in contrast, a lump sum is granted, which differs according to the services or the informal care provision that is used when the claimant is in need of the defined minimum support. In Germany, both criteria are taken into account when calculating the benefits, i.e. the level of assistance and support needed and the preferred type of care, i.e. informal care, home-based formal care services or residential care.

Critics in Germany complain that the orientation towards daily activities neglects the needs of people with mental or psychological disorders and their need for supervision, e.g. elderly people with dementia. A supplementary yearly lump sum for care-dependent beneficiaries with mental or psychological disorders was introduced in 2002 to relieve the burden of the informal carer and enable them to purchase additional services (Theobald 2004). Further criticism applies to the eligibility criteria, which specify minor needs as a private matter. In The Netherlands these minor needs are covered, but the overall costs of the insurance have been reduced with the introduction of the family-based selection criteria. Here, assistance benefits are granted even in the case of minor needs when the claimant cannot draw on adequate informal support. However, in contrast to the regulations in Germany, Austria or Flanders, only limited benefits are granted in a situation with substantial care needs when an adequate informal network is available (Deutscher Bundestag 2002). Despite the criticism of the eligibility criteria, the introduction of the long-term care insurance in Germany with its change from the formerly selective, means-tested allocation principle to a universal principle, has led to an expansion in the number of beneficiaries. In 2001 approx. 2 million people or



22% of all elderly people over 75 received different types of benefits. Naegele and Walker (2002) estimate that about 80% of the care-dependent people are covered by this insurance.

### 3.3.2 Assessment Procedures on National and Local Level

Simultaneous to the introduction of long-term care insurance with its need-based, universal and individual-orientated allocation principle, assessment procedures were defined on a national level to secure fair and equal access to the benefits. In Austria and Flanders, where income-related co-payments are calculated by service providers, additional assessment procedures were established on the local level, which take the level of need and/or the income-situation of the individual care receiver into account. The procedures on the local level allow for different decision making processes, but can result in unequal calculation of the co-payments and in effect, an unequal use of the services (Egger de Campo/Just 2003, Cuyvers/Pintelon 2003)

In their cross-national comparison, mainly between northern and southern European countries, Blackman et al (2001) showed that the establishment of a formalised assessment procedure linked to strict eligibility criteria is a decisive step towards fair access to social care services. They state that the formality of the assessment process established on a local level in the United Kingdom, Norway and Denmark is important, because it allows the services to be accessed by everyone and prevents variations in the eligibility criteria. In the daily practice of social care professionals, however, a difficult balance emerges between formally defined entitlements and day-to-day flexibility. In the UK, research on the assessment of needs by social care professionals has found the level of need decisive for the inconsistency. While high levels of needs are assessed more consistently, there are marked variations in the same cases for elderly people with low and moderate needs (Blackman et al. 1998).

In Sweden, the local responsibility for the establishment of assessment procedures in the strained economic situation of the municipalities have resulted in the implementation of more restrictive guidelines on the local level, despite the unchanged national policy. The municipalities have introduced both stricter interpretations of "needs" and wider definitions of individual or family responsibility. Regarding minor needs, e.g. assistance with housekeeping services, means-testing is now a standard procedure in most municipalities. Even the family

situation is taken into account during the assessment procedure. In particular, older married women who take care of their frail elderly husbands are increasingly left outside the municipal care services. This means a twofold departure of the allocation principles of the national social care model in Sweden on the local level, which is based on the principles of universalism and individualism (Szebehely 1999; Stark/Regner 2002, Trydegard 2003).

### 3.3.3 The Consequences for Vulnerable Groups of Elderly People

As a result of her cross-country comparison, Tester (1996) emphasises the establishment of social rights and corresponding (national) assessment procedures not only as decisive for the development of regional or local inequality but also for inequality between socio-economic groups, gender and ethnicity. Access to services and to relevant information depends on the socio-economic class, gender and ethnicity and age of both the older person and the (informal) carer and the interaction of both factors. The advantages of earlier life are passed on into older age, thus the socio-economic group often determines the financial and other resources, which can be used to gain access to long-term or social care. People with higher pensions and better insurance can buy private services and they are more likely to have a greater knowledge of their rights. In contrast, people with low pensions, especially those who are disabled and have higher care needs may have less access to the information, which would enable them to make choices and to buy and select services. Ethnic minorities and black people often belong to this group and are often not very well informed about their rights and depend thus on public services not adapted to their cultural needs or on informal care.

Women tend to live longer than men and are more likely than men to have more disabilities in later life or to be care providers. They are usually low-paid or unpaid and are less likely to have the financial resources to make choices about where they live, their care and leisure activities and are therefore more dependent on publicly funded services. This gender difference is often reinforced in oldest age and shows that women have the least resources but the highest needs in housing and care. Gender inequality is enhanced by the expectations about gender roles and leads to differences in the care services given to men and women.

Tester (1996) attributes the differences in access to services partly to the fact that there are few social rights to community care, in particular to housing and social care services. Efforts

to establish eligibility criteria based on needs, universalism and individualism and to define assessment procedures, which are visible in the long-term care policies during the 1990s especially in central and northern Europe, mark one step forward in regard to the availability of services for all user groups. However, the granting of basic rights only, the neglect of minor needs and the introduction of rationing principles in the assessment procedure on the local level impede access to services especially for vulnerable groups of elderly. The quality of services, which are allocated after means-testing to the poor only, is often quite low. Furthermore, if allocation principles and assessment procedures are not viewed as fair by the individuals themselves, this may result in a lack of trust towards public authorities and the society as a whole and contribute to the development of processes of social exclusion (Wessels/Medierna 2002)

### 3.4 Services: Organisation, Integration and Orientation

The access to different types of care services forms only one precondition for the establishment of a comprehensive care arrangement for the individual care-dependent elderly person. The fragmentation of different types of social and health care services is criticised as a further obstacle. As a result of their cross-national comparison, Blackman et al (2001) view the fragmentation and the lack of co-ordination as a risk that could lead not only to less adequate care arrangements but to the marginalization of the elderly. They opt for the development of an integrated social and health care service under the premise of a social model, which takes the social and economic conditions of an individual into account. From the point of view of Blackman et al (2001), inclusive services are defined as integrated service offers in a wide range of areas, which thus enhance inclusion and prevent marginalisation.

Efforts aimed at establishing more co-ordinated service facilities have been a major topic on the social and health policy agenda since the 1990s. The measures were introduced parallel to newly-defined goals and comprehensive restructuring processes in service delivery and funding within the area:

- Newly-defined policy goals in elderly care stress the development of integrated home-based care and social care services to enable the elderly to remain in their homes for as long as possible.

- A trend in health care policy towards shorter stays in hospital settings and an emphasis on outpatient treatment needs the integration of home-based health care and social care services to deliver a comprehensive care arrangement.
- A devolution of the responsibility for the planning and co-ordination of health and social care services on the local level aimed at improving the adaptation of care services to the requirements of people in the individual local areas.
- On an individual level, the introduction of case management services aimed at supporting the establishment of individualised and more flexible care and lowering costs.
- A reduction in the role of the state as service provider and the promotion of commercial, non-profit and informal sectors in service delivery aimed at providing more freedom of choice for the users, increasing competition and resulting in more cost-effective services.

#### 3.4.1 Diversification of Care Facilities

The changed policy goals in elderly and health care have led to the establishment of a wide range of service facilities suited to different care needs. Glendinning (1998) describes the measures as opening-up the boundaries between residential and home-based care and between health and social care services. Since the 1990s, most western European countries began to establish a continuum of social and home-based care services and semi-residential and residential varieties of housing opportunities, respectively. In their cross-country comparison, Pacolet et al (2000) found a gradual disappearance of the traditional old age home as the main type of residential living and the emergence of new and different types of adapted housing facilities. The first institutional type, mainly nursing homes, can be described as a care facility orientated towards medical care aspects for care-dependent elderly with a high level of care needs. In most countries a convergence can be observed between old age homes and nursing homes with the increasing adaptation of old people's homes to nursing homes. For elderly people with lower levels of care need, new types of housing have been established to support a more independent life style. Pacolet et al (2000) summarised the different forms of sheltered housing where the elderly still live in their own, e.g. barrier-free flats combined with alarm systems and common rooms and care service offers as the second type. The third type is adapted housing, which is the renovation and restructuring of a care-dependent person's own

home to suit their care needs, such as barrier-free living conditions, larger bathrooms and the opportunity to use a wheelchair.

Intermediate services, such as day care and short-term care facilities, allow the elderly in need to spend intermittent spells in nursing homes or residential homes, or those who are in need of assistance during the day-time to stay permanently in their own homes. The services were also introduced to unburden the informal carer and thus support domestic care (for greater detail see section 3.6). In some countries like Germany, Belgium, Italy, Portugal, Sweden and UK, the establishment of multi-level facilities, which comprise of home-based care, semi-residential and residential care offers are in the planning stage (Pacolet et al 2000). The level of permanent residential or semi-residential services differs from country to country. High level, well-developed services can be found in Denmark, The Netherlands, Norway and the UK. In Austria, Belgium, Finland, France, Germany, Ireland, Luxembourg and Sweden there are medium levels, whereas in the Mediterranean countries, with their family-based care approach, such services are still underdeveloped (Pacolet et al 2000).

The emergence of a chain of housing possibilities, suitable for the elderly with different levels of care needs, as well as intermediate services enable elderly people to remain in their homes longer and to lead a more independent life. However, the preventive character of the offers can be inhibited by funding policies. In most European countries, state subsidies vary for the cost of this type of housing and can thus result in high costs for the elderly themselves. In Germany for example, in contrast to the care services, accommodation costs for sheltered housing are determined by the market and are not regulated by the insurance or the state. Despite the possibility of receiving housing-allowances, in Baden-Wurttemberg for example, the leading individual federal state in this respect in Germany, there is a reported lack of sheltered housing facilities for elderly people with lower incomes. Furthermore, in contrast to residential care, the costs of services in home-based care must be paid according to each individual care activity, resulting in higher costs for severely care-dependent elderly people (Theobald 2004).

### 3.4.2 Integration of Different Types of Services

Living in one's own home, despite a high level of care-dependency, necessitates a comprehensive care offer. In some countries such as Denmark, The Netherlands and Northern Ireland more intensive care services, comparable to the level of nursing-home care, have been established for the elderly in their own homes to prevent nursing-home admissions (Glendinning 1998; McCormick/Harpur 2003). Coleman (1995) views the discouragement of institutionalisation and the flexible programmes of assistance around the clock as a promising pattern for the development of home-based long-term care in European countries. In addition, the changing health policies in most European countries, with an increasing emphasis on treating acute illness on an in-patient basis only, have strengthened the demand for the integration of basic and specialised nursing care services and different types of social services.

According to Glendinning (1998), the measures that have been introduced to facilitate the co-ordination of services on the organisational level include setting up co-ordinated networks of providers, interdisciplinary teams of home care workers and nurses and financial impetus to improve the co-ordination between the hospital and the community services. She also states that the relationships between social service home care staff and community nurses are already often close at the operational level of the so-called 'front-line' services, but views this as depending on the individuals involved and pertaining merely to the co-ordination of service delivery rather than to broader strategic issues of service planning (Rummery/Glendinning 1997).

The development of integrated care systems is a process where institutional structures, forms of co-operation, social relationships as well as status, power and the income relations of different professional groups are involved. In consequence, processes of integration cannot simply be planned and implemented, but demand time and opportunity to develop new forms of co-operation in the day-to-day activities. Thus, the creation of innovative and more integrated care systems is impeded in a situation of employees' social insecurity (Kühn 2001).

In Sweden for example, the Ädel-reform, named after the initiator, is aimed at gathering all public care for the elderly under the authority of the municipalities and strengthening the social service culture and de-medicalising the care of the elderly. The reforms have

simultaneously provided a strong financial incentive for the municipalities to offer home-based care for hospital patients on their discharge (Trydegard 2003). Between 1992 and 1996, the number of hospital beds has been halved and the average stay in hospital has dropped from 11 to 7 days. The trend was especially pronounced in geriatric hospitals and clinical wards and shows a decline from 52 to 22 days in 1996. Most of the patients who are now taken care of at home are elderly people (SOU 2000; Landstingsförbundet 2002)

But the outcomes of the Ädel-reform are ambivalent. Even ten years after the reform, co-ordination problems still remain between the municipalities, now responsible for the nursing homes and the different types of home-based care and the county-councils, the executive body for doctors' services (Trydegard 2003). The Ädel-reform practically compounded two diverse working-styles and orientations in the area of home-based care. The home help services of the municipalities, orientated towards the social model of service delivery used to work with home-nursing services organised by the county councils, which are orientated towards the medical model (Runesson/Eliasson-Lappalainen 2000). The strained economic conditions in the given time-period have impeded the development of a common model or perspective for the former home helpers and the nurses. Furthermore, the increasing care needs of the elderly after earlier discharge from hospital, have consumed a much higher proportion of the care resources than anticipated. The municipalities are focused on personal and nursing care for severely care-dependent elderly people, while neglecting their need for housekeeping and social commitment, thus leaving elderly people with minor care needs without any assistance from the municipal home services. In the course of its implementation, home-based care has become even further orientated towards the medical model, in contrast to the aims of the Ädel-reform (Trydegard 2003).

Cross-country comparisons view the retraction of many low-level services, such as assistance with housekeeping or leisure/social activities and thus the loss of their preventive value for the elderly, as one of the major problems in the development of care services (Blackman et al 2001). The integration of different types of care services under a social model, i.e. including the assistance with social activities or low-level services, is assessed by Blackman et al (2001) as a basic quality of inclusive services. Despite the difficulties with the implementation, the researchers assign the Scandinavian countries and their efforts to establish one model under the authority of the municipality, the potential, at least, for the development of more inclusive, comprehensive services.

The devolution of the executive power and responsibility to the municipalities or regions in some countries is aimed at adapting the care services to the individual needs and to the risk structure in the local area (Glendinning 1998). In addition, the planning and co-ordination of the services on the local level allows citizens more influence on the decisions in the care sector (Kühn 2001). Despite the advantages, this emphasis on local level responsibility in the co-ordination and the planning of care raises the question of equity and citizenship, i.e. the issue of regional inequality. The question that arises here is whether and how national frameworks can be constructed to guarantee equal access to services in the country as a whole and at the same time be combined with opportunities for decision-making on the local level. Glendinning (1998) argues that the devolution of responsibility makes the overarching regulatory frameworks even more vital so that elderly people are able to receive equal access to citizenship-based services.

The typical local autonomy of the Nordic countries has led, in Norway for example, to variations in the volume and variety of services across the municipalities (Lingsom 1997). In consequence, demands have arisen for the establishment of stronger national norms and standards as well as a more direct involvement of the national level of monitoring local authority care activities (Daatland 1997). In Sweden, the strengthening of local responsibility within the area of elderly care, where the municipalities enjoy great freedom of decision on the scope and volume of their services and in the definition of the eligibility criteria and charges for the services, has led to unequal access to care for the elderly. The coverage in home-based care for elderly people over 80 ranges from 8% to 30% across the municipalities, while the differences cannot be explained by factors such as the age structure, the needs or even the economic conditions within the municipalities. It seems more likely that during the 1990s, the municipalities reduced the number of care receivers due to financial constraints, making the different standards even more pronounced from the very beginning. Sweden has shown recent signs of re-centralisation, an example of which is the central government decision on the so-called law on maximum fees, which came into effect on July 1<sup>st</sup> 2002. This law defines the upper limit for the fees that can be charged for care services by the municipalities (Trydegard 2000, 2003)

In addition to the efforts being made to co-ordinate different types of care services on an individual level, case management has been recommended as a mechanism for tailoring service inputs to the specific requirements of individual users. Both the integration of



different care services and the establishment of suitable care arrangements for the individual users are seen as supplementing each other (Kühn 2001, Blackman et al 2000). The ambivalent role of the case manager can be clarified by an analysis of the different functions, which are emphasised specifically according to the context and the definition of the working-tasks (Ewers 1996, 2000). In their advocacy function, the case managers represent the interests of the users by establishing a suitable care arrangement and by suggesting changes in the services offered, the modes of service delivery and the funding, etc., based on the knowledge of the needs of the individual users. The case manager also has a broker-function with the emphasis on the neutral role of arranging care services to suit the needs and wishes of the so-called customer. Finally, as a gate-keeper, the case manager must consider the economic issues with the goal of establishing the most cost-effective care package and thus impeding the unchecked access to the collectively funded resources. The interplay of the different functions is revealed in the example of the integrated budgets, which form a common budget for the funded services. These budgets offer the opportunity to purchase service packages from different providers and to develop a comprehensive care arrangement. However, empirical studies show that these budgets can easily be capped when they are aimed at maximising cost-effectiveness (Glendinning 1998).

Case management services are especially significant for care users with complex needs, e.g. elderly users with chronic illnesses (Garms-Homovlova 2000). Empirical results confirmed different user rates for care services according to the users' social position in society, their gender and ethnicity (Baldock/Ungerson 1994; Altenbericht 2000). Vulnerable groups in a society, e.g. with a lack of education or with a low income, often have less information and can draw less on further resources to build up their own care arrangements.

The ongoing process of privatisation of services increases the problem of fragmentation of services and contributes to the creation of inequity (Coleman 1995) Competition between different providers gives the impression that there is a greater choice and control for the care users as "consumers". But operating as a consumer of care services necessitates a certain degree of confidence, competence and/or private means. Consumerism does not equate to citizenship rights and it can be difficult for large groups of elderly users to take advantage of the different service offers and the opportunities of choice (Glendinning 1998). In particular, vulnerable groups of elderly people tend to act less often as sovereign customers on the care services market and are more dependent on advice and support. They are often more likely to

leave the choice to professionals and accept their choice, even if this is not what they would prefer themselves (Tester 1996; Stötzner 1999; Kühn 2001)

Inclusive care services, i.e. services which prevent or counteract processes of social exclusion, are defined by different characteristics, such as oriented towards a social model of care delivering, and the provision of integrated and comprehensive care services (Blackman et al 2001). The development in this area since the 1990s proves to be ambivalent. The expansion of a variety of services and efforts to integrate them on a systemic and an individual level supports social participation of care-dependent elderly. However, the obstacles in the process of integration, the establishment of different service providers in the same area and the still prevalent orientation towards a medical model of care delivering and thus the neglect of the life-situation of the individuals as a whole strengthen the risk of the development of processes of social exclusion.

### 3.5 Domestic Care: Formal, Informal Care and Negotiation Processes

Despite the expansion of formal care services, informal carers still provide the main bulk of care for the elderly. Changes in the welfare mix are not only congenial to the proliferation of the marketisation of the services, but also raise an increasing awareness of the important contribution of informal care and the efforts being made to consciously examine the interplay of formal and informal care.

#### 3.5.1 The Interplay of Formal and Informal Care

Different models have been conceptualised and empirically investigated in the analysis of the relationship of formal care services and informal social care. The substitution model proceeds on the assumption that needs and the corresponding caring tasks have a final character (see Daatland/Herlofson 2003a). Both paid and unpaid carers can carry out the necessary caring task and are seen thus as functionally equivalent and substitutable (Lingsom 1997). From the perspective of this model the changing family structures with the expected decrease in informal care, require the development of paid social services, which in turn reinforce the decline of informal family care. This argument is usually put forward by critics of the

expansion of paid formal home-based care services, who warn of the risk of a further weakening of family ties due to paid social services (Denton 1997).

The complementary model views needs as socially defined and not as final. It emphasises the processes of negotiation between paid and informal care workers where needs and caring tasks have to be discussed and agreed upon. Within these negotiation processes, the welfare states, which have the capacity to define the needs, responsibilities and standards, play an active role in delivering a framework for discussion. The complementary model contains two formulations, the family support and the family specialisation hypothesis (see Daatland/Herlofson 2003a). In contrast to the substitution model, the family support hypothesis assumes that professional services reinforce informal care, because they lower the burden on the informal carer and both informal carers and care receivers are therefore more willing to give and to accept informal care. The family specialisation formulation draws on the task specificity model of Litwak (1985) which assumes that both formal and informal carers have a specialised competence, their own internal logic and subsequently different roles in the provision of care. He argues that formal services are more suited to the performance of technical or more skilled tasks, e.g. nursing care, whereas informal carers have a greater eligibility to give emotional support or to provide assistance in the day-to-day activities. In consequence, the formal services must be active in those domains where formal carers show specific competence and vice versa.

Empirical findings demonstrate explicitly that the substitution of informal care work by formal care services is not a very common phenomenon (Denton 1997). In contrast, research findings show no substantial reduction in the levels of family help even in more service orientated countries (Daatland/Herlofson 2003a). The link between formal and informal care is revealed as a multifaceted interplay, which depends on the family situation, the level and type of help as well as the approach and the organisation of formal care services in a given country. Chappell and Blandford (1991), for example, found evidence of the family support formulation and proved that there is an increasing significance of formal care when a care receiver's health deteriorates. On the basis of the analysis of the link between formal and informal care in a national Canadian sample, Denton (1997) confirms the complementary assumption, but emphasises the significance of informal care in the different care tasks as personal care or light, respectively, heavy housework. Both the formal and informal carer

conducted the caring tasks in the same area, thus, there are no indications in the data for a strict division of caring tasks between formal and informal carers.

In a European comparative project, the interplay of family help and formal services has been compared in both the more service-orientated and more family-orientated care systems (Daatland/Herlofson 2003a). Their initial findings show that in countries with a high service orientation, far less elderly people remain without help in case of need. Secondly, in accordance with the family specialisation hypothesis, new forms of partnerships between paid and unpaid carers evolved when families took over functions that were only rarely delivered by formal care services, e.g. emotional support or transport services. New family tasks have even been developed, e.g. the function as a case-manager, i.e. with family members organising and integrating the different service offers.

The establishment of co-operation between the informal and formal carer requires the acknowledgement of a partnership between professionals and the non-professional informal carers. The professional carers have to develop insight into the competencies of the informal carer, based on the latter's day-to-day experience with the care receiver as well as into the psychological and social consequences of their care task. The informal carers are very often exhausted and in need of support and unburdening and quite gratified when they receive the opportunity to make decisions about their own sovereignty and on the extent of care they choose to provide. The use of professional care services gives informal carers the opportunity to build up new relationships and negotiate the care tasks (Älreduppdraget 99:2; Tjadens/Pijl 2000) In contrast, as a result of their professional training and their mandate, many professional carers are orientated towards the needs of the care receiver and tend to neglect the experience and competence of the informal carers. A change in the system is essential if the attention is to be directed not only towards the care receiver but towards the individual situation of the carer, thus including the entire care system (Tjadens/Duijnste/Pijl 2000).

### 3.5.2 Negotiation Processes within the Family Framework

The availability of services embedded in a specific social care approach in a welfare state defines the responsibilities and the support that a state delivers in a defined situation of need, thus providing the framework for the establishment of an individual care arrangement. The

way the family members take over the responsibility of care has been revealed to be a matter of negotiation where the definition of family responsibility is decisive, rather than only the availability of services and support systems for informal carers. (Daatland/Herlofson 2003a). Within the negotiation process, publicly expressed norms on responsibilities and duties attached to the family do not seem to be acknowledged automatically. Family responsibilities do not operate by way of substantive fixed rules showing what must be done, but are acknowledged as procedural guidelines, which indicate how to work out the appropriate level of help and assistance to relatives in defined situations of need (Finch 1989; Finch/Mason 1991, 1993).

Specific circumstances within the negotiation process distinguish whether or not people tend to agree that family members should give support and assistance. It is more likely that assistance is provided when the family member needs it, i.e. the situation is not culpable and the need is legitimate. Furthermore, support is provided more often in a situation of fairly limited assistance in terms of time, effort and skills. Finally, due to the special status assigned to the parent-child relationship, people usually agree that children have a responsibility to do something to support their older parents, but views vary on what they should do.

Finch and Mason (1991/1993) emphasise the importance of agency, processes and procedures in the course of the negotiation of family responsibilities. Present actions are only understandable on the basis of existing commitments of giving support to each other and are developed in the course of the individual biographies. Thus, family responsibilities are not automatically connected to the family status but are created in a biography embedded in the individual family context. In their research, Finch and Mason (1991/1993) found no systematic variations in their empirical research for procedural guidelines of social position, class or ethnicity. The importance and influence of social position necessitates a new definition of social structure. They define the term 'effective structural position' to examine not only formal definitions, but to investigate how the position constrains the human agency. They explain the high involvement of women compared to men in informal care arrangements, with the different sets of reciprocal commitments that men and women often develop with relatives. Hence, the effective structural position of women is decisive for the development of commitments and for their mode of enactment or the type of assistance family members provide to each other.

In international comparative research in the area of elderly care, the gender differentials in taking on informal care tasks are confirmed as valid for all countries. The vast majority of carers are still women, mainly spouses or daughters (in-law). Men take over more traditional caring duties in partner relationships, while in non-partner relationships, they tend to be active in the area of logistics or care management (Jani-Le Bris 1993). The findings on the normative level and in day-to-day practice in regard to the influence of ethnicity or social class are less lucid (Daatland/Herlofsson 2003b; Bazo/Ancizu 2003). There is evidence in some countries, such as the United Kingdom, The Netherlands and Germany that people with a lower educational attainment level are more likely to be active as informal carers (Klie/Blinkert 2002; Tjadens/Pijl 2000).

The distinction between the acceptance of responsibility for the care of elderly relatives and its mode of realisation offers a starting-point for the explanation of the contradictory results. Findings show that the acceptance of family responsibility can result in actual service provision by family members, but can also be responded to by organising and managing the appropriate social care. The availability and the access to paid social services provide an opportunity to choose an adequate strategy. The paid social services are more often involved in care activities in urban settings where social services have already been established (Daatland/Herlofsson 2003a).

Besides the available care services, there are several dimensions characterising the situation of the informal carers within the negotiation process that can influence their decisions. The dimensions of time, effort and necessary skills, already described by Finch and Mason (1991, 1993), must be extended to include the dimensions of estimated psychic, economic rewards and the cost of alternatives (Mundt/Lusch 1997). In the rationale of the decision, the idea of the quality of care is also put forward based on sentiments of trust and control. High quality care can be assigned to informal care, to home-based care and to formal care in residential homes.

The influence of the social care approach in welfare systems and its interrelationship with the life situation of the female potential informal carers has been illustrated in a German-Swedish comparison, where the service orientation of the Swedish elderly care has led to less class division in the decision on formal or informal care services (Theobald 2003). In contrast to Sweden, where care dependency entitles the dependent to service provision only, care-

dependent people in Germany can choose between cash benefits and home-based services. The freedom of choice between the two alternatives has led to social class divisions in the emerging patterns of care-arrangements. Members of the upper middle class choose services instead of cash payments more often than members of the lower classes (Blinkert/Klie 1999; Giese/Wiegel 2000).

In the analysis of the background of the class division between cash payments and professional services in general, i.e. home-based and residential care, Klie and Blinkert (2002) compare the influence of the structural characteristics of class, e.g. the income and educational attainment level, with the gender and family orientation on a normative level. They found that in the negotiation process, the influence of the structural characteristics became more decisive than the norms. They explain the different action strategies of the female potential carers as dependent on the economical situation, i.e. the costs for professionalised services (in their example) especially for residential care as well as the opportunity costs for women to leave the labour market to carry out informal care tasks. Compared to non- or lower educated women, the better labour market position and the future career prospects of the more educated women increase their opportunity costs when they leave the labour market. In addition, the more flexible working-time arrangements typical for the situation of higher-educated women support the opportunity of combining care for a family member and gainful employment. (Beck et al 1997).

### 3.6 Informal Carers: Social Role and Support Systems

In most western European countries, the increasing awareness of the importance of informal care and at the same time its fragility within changing family structures has led to a debate on the role of carers in society and on the efforts being made to create new forms of support. While at the beginning, the social, psychological and financial situation of the carers dominated the debate, issues such as the rights of carers to social participation and to a life of their own as well as the right to care or not to care have been gaining significance of late. (Blackman et al 2001; Tjadens/Pijl 2000; Pijl 2003).

Taking on caring responsibilities is not usually based on a conscious decision to become a carer, but rather on an event in the life of a close relative, e.g. when a parent becomes

increasingly frail. Carers do not tend to view themselves as carers with the subsequent rights of support, but rather as spouses or daughters of the care receivers. This causes difficulties when approaching them and offering support that could prevent overburdening and enhance the positive qualities of care work. It appears to be important that support is offered to them personally. In the United Kingdom, for example, the role of the general practitioner is emphasised as a point of identification and information for carers, opening up access to further support. But this task is still neglected, despite the present demand (Pijl 2003).

With the introduction of the Carers and Disabled Children's Act in the United Kingdom in 2000, the informal carers became entitled to request an assessment of their ability to continue caring. The law is aimed at targeting and improving support for informal carers but its effects are considered negligible. Within the context of this law, no extra-funding is provided either for the assessment procedures or for possible essential services. Independent of the result of the assessment, the local levels are not obliged to provide services for informal carers and the latter must compete with the care recipients for the available service funds (Tjadens/Pijl 2000; Pijl 2003). Further criticism on the approach itself is that in the course of the assessment, informal carers are regarded as care receivers in need of societal support, which neglects their major contribution to the area of care. Demands have been made to consider informal carers as care providers instead, equipping them thus with rights and opportunities comparable to the personnel policy measures for professional carers. This includes the right to information and training, the possibility of a dialogue with colleagues and the right to counselling and the provision of assistance when the workload gets too high (Pijl 2003).

From the perspective of informal carers, their work comprises of costs and benefits and both of these must be considered when developing appropriate support systems. Caring work costs are named as emotional costs, e.g. witnessing the physical decline of the loved one, the physical cost due to the burden of the care involved, the stress in other relationships due to the caring burden, the loss of independence and the loss of income or increasing financial costs. But there are benefits such as pride at the discovery of unknown capacities within oneself, a new meaning to one's life, the satisfaction in supporting a close relative or friend or in gaining social approval while fulfilling a moral role (Jani-Le Bris 1993).

In the analysis of the burden of caring work, three categories can be distinguished that interact differently according to the individual care situation (Tjadens/Pijl 2000):



- horizontal burden (the areas in which the carers feel a burden)
- vertical burden (the level of the burden experienced in each area)
- continuous burden (the possibility from a carer's perspective of reducing the burden).

Research findings also reveal that there are different types of carers involved in different types of care activities, e.g. a distinction must be made between the carers of elderly people suffering from dementia illness, carers of ethnic minorities, older spouses or working carers (Drewett et al 1995; Parker/ Lawton 1994, Patel et al 1998; Pijl 2003 ). The results show that despite similar elementary needs, the ways in which these needs are met must be flexible and adapted to the situation of the individual carer.

Support for carers can be divided up into the following basic forms (Jani-Le Bris 1993; Tjadens/Pijl 2000; Pijl 2003):

- Advocacy, information, guidance and counselling
- Emotional support
- Financial support
- Respite care
- Leave from work, flexible working-arrangements

In western European countries, information, advocacy and counselling as well as emotional support is provided by a wide range of actors on the local level, i.e. by the carer's organisations, parishes, municipalities or care insurance funds (Tjadens/Pijl 2000). The provision of financial support for carers and the establishment of a social right to respite care for informal carers were major topics of the social policy agenda in the 1990s, leading to the provision of extra funding for these services and creating appropriate forms of funding.

Rising costs can be considerable in the process of caring. They include direct costs such as co-payments, medical aids, transportation, etc. and indirect costs due to the loss of income because of the reduction or interruption of gainful employment (Tjadens et al 2000; Pijl 2003). Different forms of payment have been introduced in western European countries to equalise both the cost of care and the provision of care within the care receiver's own home. They range from a mere gesture to wage replacement compensation as well as the financial means to purchase further services (for greater detail see section 3.2.2).

The services that are already established for the care receiver can be viewed as the first step towards unburdening informal carers. The Royal Commission Report on long-term care in the United Kingdom, for example, suggests that care and social services should be offered at the same level to the most dependent older people being cared for by their spouses just as for elderly people living on their own. The main efforts, however, relate to the introduction of entitlements and opportunities to different types of respite care (Pijl 2003). In Finland, informal carers receiving Home Care Allowances were granted the legal right in 1998 to two free days a month. The municipalities there must offer substitute services for which they can charge fees. Under the terms of the long-term care insurance in Germany, informal carers are entitled to four weeks respite care and to four weeks short-term care in the occurrence of a crisis in the care arrangement situation. If the costs of the services exceed the insurance benefits, further costs have to be paid out of pocket, depending on the care receiver's level of frailty. Day-care services can also be financed by the benefits of the long-term care insurance as part of the payment granted and thus in competition to other services (Theobald 2004).

In The Netherlands, the General Extraordinary Medical Expenses Act, which applies to the area of long-term care, grants payments for use in short-term care and day care facilities. A number of facilities for respite care were established during the 1990s, enabling short stays in residential homes or separate facilities set up by the municipalities or provinces. Volunteer schemes have been introduced, which allow volunteers to go into the homes of care recipients and thereby offer informal carers the opportunity to take a break. The professionals running such projects are funded by the insurance (Pijl 2003).

Figures in The Netherlands and Germany show insufficient take-up rates of such services. This is explained by the costs, the lack of flexibility and adaptation to the situation of the individual carer as well as the criticism of informal carers on the quality of such care facilities (Theobald 2004; Pijl 2003). As a result, efforts have been made to adapt the services and the funding to the needs of the individual informal carers. In the United Kingdom, the National Strategy for Carers provided extra-funding of 100 Million GBP between 1999 and 2005 to give carers the opportunity to take a break. A simultaneous goal of the funding was to stimulate new, flexible and diverse service offers. Despite difficulties at the beginning, research findings describe examples of good practice.

The flexibility of services has been expanded by:

- Increasing the opening hours of day care services, e.g. at weekends
- Extending services going into people's own homes
- Adapting services to the needs of minorities
- Opening up more opportunities for choice
- Providing mobile services in rural areas

Respite care opportunities enable informal carers to have time off for recreation and to have more time for themselves generally. In the context of the recent debate on the issue, the goals have been extended to emphasise the right of informal carers to social participation, i.e. integration into the community and the opportunity to continue work. The increasing opportunity for social participation, despite caring responsibilities, is meant to enhance the quality of life for the carers. Fostered by the increasing labour market participation of women, the issue of working carers has been put on the agenda and the measures are aimed at creating better conditions to help the carers to stay in employment and to return to employment when the caring process comes to an end (Pijl 2003).

In Nordic countries, the strategy of labour market participation for women was realised by the development of a variety of universal services. Only modest employment and income effects are found as in the case of Norway, which has implemented a strategy allowing informal carers, mostly women, to stay on the labour market. (Lingsom 1997; Ellingsaeter/Hedlund 1998). In the United Kingdom and The Netherlands, a national strategy has been adopted to support informal care rather than displace it (Blackman et al 2000; Pijl 2003). In The Netherlands different forms of paid leave allow informal carers to stay on the labour market while simultaneously carrying out their caring-tasks. The measures here range from the right to "Calamity-leave", i.e., to ten-days leave to take care of a sick child or an elderly person in case of an emergency. Furthermore, a proposal has been worked out to grant the right to long-term care leave and can be used for the duration of six times the weekly hours within a 12 weeks period in a situation when a partner, parent or child is terminally ill or has a life-threatening illness.

The acknowledgement of the right to care or not to care is being increasingly brought forward as a basic issue within the social-political debate, i.e. the informal carers should be allowed to

decide for themselves whether they want to take on caring tasks and if so, to what extent. In most countries the social regulations, payments or publicly funded services are not in a position to grant this right for the whole population but at the same time expect a major contribution from informal carers. In The Netherlands, for example, during the assessment procedure of the care receiver, the informal care resources are taken into account and determine the level of granted services. The carer organisations criticise this practice while arguing that in many cases, the informal carers are forced to do more than they are ready to do (Pijl 2003).

Within the area of informal care the issue of social exclusion concerns both, the situation of the care-dependent elderly and the situation of the informal carer. For the establishment and maintaining as well as the adaptation of a comprehensive care arrangement the role of the informal carers is pivotal. The obstacles described above, i.e. the lack of cooperation between formal and informal carers, the difficulties of the combination of the different types as well as the heavy burden carried by the informal carers and the lack of adequate unburdening measures, impede the establishment of an adequate care arrangement and thus enhance the risk to trigger processes of social exclusion. From the perspective of the informal carers a heavy burden impedes their own social participation. Furthermore, the regulations in this area in different countries in interaction with the situation of the informal carers and care-dependent elderly may enforce the informal carer to take on more care responsibility and care work as they want to do or in the long run are even able to do.

#### 4. Conclusion: Social Exclusion, Social Care and Inequality

The concept of social exclusion was developed as a tool to analyse “new” social cleavages in society, i.e. the situation of the members at its fringe. The concept emphasises the cumulative interplay of different dimensions, the social, institutional, cultural, economic and spatial dimensions within the process of social exclusion. Transferred to the area of elderly care, the concept is used to evaluate the capacity of care systems to enhance the social inclusion of elderly people and despite their care-dependency, promote independence and avoid negative dependency. "Inclusion" as an outcome criterion is extended to contain the procedural criteria that define the access and the use of services.

There has been an increasing acceptance of public responsibility for long-term care delivery in most western European countries during the 1990s. Especially in the Central European and Nordic countries, the modes of funding and types of benefits have been restructured or introduced, while the Southern European countries still assign the major responsibility for elderly care to the family. The establishment of a (near) universal principle, the orientation of the benefits towards basic long-term care needs and towards the situation of the individual claimant are characteristic of the new modes of financing. The assessment procedures on a national or local level are aimed at guaranteeing equal access as well as targeting the benefits towards certain defined needs. A growing awareness of the necessity for a comprehensive care offer has led to efforts towards developing more integrated services and acknowledging and supporting informal carers.

The outcomes of the changes in funding, organisation and orientation of the individual care approaches are many-faceted and differ in relation to the user groups and informal carers. Changed funding principles in Central Europe, which emphasise the universalism and individualism and guarantee citizens at least basic care, improved the accessibility of services and have led to the establishment of a variety of long-term care services. The neglect of minor needs, such as housekeeping services or assistance with social and leisure activities, however, can be seen as a limitation, leading to a loss of its preventative value and capacity to enhance elderly people's social participation. Furthermore, the introduction of assessment procedures, as long as they are perceived as fair, increase trust towards public authorities. The targeting of resources and the unequal resource allocations, may, in contrast, lead to distrust and increase the risk of processes of social exclusion.

The care gaps left by the different care systems are filled according to the gender and social position of the specific social group. While members of the middle-classes can purchase the services on a private market, members of the lower classes are dependent on care support from the (mostly female) family members. The social participation of the carers is impeded as a result. New demands of carer organisations, which insist on the right to social participation of informal carers and the acceptance of the right of the informal carers "to take on, or not to take on caring duties" reflect the conflict between the increasing demands on informal carers and the claims of (mostly female) carers to have a life on their own. The gap increases the demand for services on the grey-market, which again are provided mostly by women of the lower classes and female migrants. In respect to care receivers, the necessity to provide either

some care on an informal basis or to purchase the corresponding services cumulates for elderly women with low pensions living alone and for older spouses with a low household income caring for their husbands. These groups may be forced to abstain from purchasing the necessary services, resulting in a care gap for women living alone or a heavier work load for a spouse.

Further limitations are found in care services that are still fragmented, which is encouraged by the trend towards privatisation. In order to use the opportunities of choice offered within the area, information, authority and social competence are needed to negotiate on services and may even require private means. The case management services, which were established to support individuals to arrange their own care, act in a situation of conflicting interests between care users and insurance demands for more cost-efficiency. The emphasis on cost-efficiency impedes the organisation of comprehensive care arrangements, especially for members of the lower classes who become more dependent on the availability and orientation of case-management. The insufficient adaptation of the services to the cultural habits and needs enhances the difficulties of migrants to build up an appropriate care arrangements.

The devolution of the responsibility and power to the local level creates a prerequisite for care services that are adapted to the specific needs of an area but this can be accompanied by increasing local inequality. These have proved independent of gender and social status but reinforce the existing levels of social and gender inequality. The experiences in Sweden, for example, show that sufficient funding and a definition of national standards on the basic issues of care delivery are essential to counteract local level inequalities. The findings confirm the necessity to analyse the risk of social exclusion from the perspective of different user groups according to gender, social, ethnic and regional inequality. Obstacles in regard to an adequate service delivering interact with the social and individual situation of the care-dependent elderly and their informal carers and thus expose them unequally to the risk of social exclusion.

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