

Day 1: Long-term care in Europe, the state of the art

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Introduction to the study

1. Introduction

The organization of long-term care for the elderly, for persons with intellectual and physical disabilities and for persons with psychiatric care needs in Europe, is rapidly changing. Predominantly as a consequence of the ageing of the European population, greater proportions of the population are becoming dependent on long-term care (Saltman et al. 2006: 720). At the same time demographic changes and the increasing labor participation of women (OECD 2004) are likely to result in a decreasing availability of family care givers. Also, technological progress and increases in private wealth modify the organization of European long-term care. On the policy level changes occur as well. Often as a result of budgetary constraints that result from the before mentioned developments, governments in some Western and Northern European countries increasingly count on citizens to contribute to long-term care provision (e.g. in the Netherlands: Raad van de Volksgezondheid en Zorg 2007: 22). Given the current economic crisis that has confronted Europe, and the resulting need for governments to make dramatic cutbacks on their spending, it seems likely that in the near future we will see this tendency all over Europe. Also in European countries with a less developed welfare state, where governments sometimes seem to have reluctantly started to take on greater responsibilities for long-term care.

As a result of the developments described above, the ways in which people try to address the care needs of dependent persons have changed. New modes of care provision have been invented and traditional modes of care provision have become less prominent. The new care arrangements often blur the boundaries between formal and informal care. Characteristics of long-term care arrangements that used to coincide (such as care at home virtually always being family care, and paid care virtually always being professional care) have unraveled in many European countries (e.g. due to the introduction of home care services, privately hired migrant home care givers and cash-for-care schemes). The changes with regard to the prominent modes of care provision can also be described in terms of a changing division of responsibilities for long-term care between citizens and the public sector. All over Europe, countries are involved in redefining the division of care responsibilities (Bettio & Plantenga 2004: 86). Especially

in Western Europe, the responsibility of citizens to provide long-term care has in practice been enlarged over the past decades.

These developments were the starting point of our study. They made us wonder what their consequences might be for citizens that in one way or another, as potential care receivers or as potential care givers, are dealing with long-term care. Three issues can be distinguished. The first issue results from the emergence of new care arrangements. This development poses a question about the *vulnerability* of the new modes of care provision with regard to their levels of *stability* and *quality*. Is care provision becoming more or less vulnerable as a result of these changes? In a time in which old modes of care provision are replaced by new ones, it is of great importance to examine the new care arrangements with respect to the levels of *stability* (are there sufficient and permanent provisions?) and *quality* (are the provisions offered good ones?).

A second issue concerns the *responsibility* shifts within European long-term care. Especially in countries with more developed welfare states, responsibilities for long-term care typically seem to be shifted towards citizens. Governments increasingly seem to count on citizens to take on care-giving, care management and financing tasks. As a result of the current economic crisis, this development is bound to spread all over Europe, also to countries that have less developed welfare states. These responsibility shifts potentially have consequences for the *inequalities* between citizens: inequalities amongst those having care needs, as well as inequalities amongst those citizens that are expected to contribute to long-term care giving. The inequalities among members of the first group are at danger of being increased because the expectation that citizens take care of the provision of long-term care amongst themselves, puts those who have less private resources at a disadvantage. However, the responsibility shifts may have consequences for other citizens as well. Margot van Trappenburg (2009) points out that “active solidarity”, as she calls the ideal and practice of expecting citizens to take care of each others care needs, increases inequalities amongst healthy and fully capable citizens as well (since the rich will be able to “buy out” their care tasks, while poorer people don’t have that option).

The third issue concerns the *experiences* and *expectations* of the European populations with regard to long-term care. Do they define existing inequalities as problematic? Do

they oppose new practices and developments within long-term care? And based on the normative expectations of governments on the one hand, and populations on the other, where can problems be anticipated? These questions alert us to tensions within European countries in the field of long-term care.

In order to allow for well-considered future policy making, it is important to gain more insights in all of these issues. We will examine these three issues one by one. First we will look at frameworks that might help us to accurately describe the changing modes of care provision in European long-term care. We need such a framework in order to assess the *vulnerabilities* of the prominent contemporary care arrangements. Secondly, we will have a look at the issue of shifting responsibilities, and the *inequalities* this potentially creates. And lastly, we will survey the indicators that we have used to grasp the *experiences* and *expectations* of the European populations on the one hand, and actual policies on the other hand.

2. In/formalization and vulnerability of long-term care provision

Now let us turn to the first of our three issues. In order to assess the strengths and vulnerabilities of contemporary forms of care provision, we will first need to find a framework that can accurately describe today's care arrangements. How care provision is organized at the *micro-level* of families and households affects not only the *extent* to which care provision at the micro-level is vulnerable. It also affects the *types* of vulnerabilities that the provision of care faces. In this section we will develop a framework for accurately describing the existing and developing modes of long-term care provision.

Several conceptual frameworks for describing long-term have been proposed. Much of the existing literature broadly refers to formal and informal care, but does not operationalize these concepts in a way that allows examination of those factors most likely to influence the vulnerability of care arrangements.

Four types of distinctions are often made between **formal** and **informal** care, depending on whether the focus is the *payments*, *labour market*, *relationships* or *location* involved.

Some authors focus on the issue of payment and thus distinguish between *paid* care and *unpaid* care (e.g. Pommer et al. 2007; Wolf & Agree 2004). Others stress the issue of way the labour market is involved, and therefore focus on whether care work is done (or not) as *officially registered employment* for which tax payments and nonwage labor costs are made (e.g. Bettio & Plantenga 2004; Lyon & Glucksman 2008; Pfau-Effinger et al. 2009). A third group of authors is most occupied with in the kind of relationship care givers have with the cared for and interprets informal care as care by *family members or acquaintances* (e.g. Ten Have 2004), which is then contrasted to formal care as being occupational (De Boer 2005), professional (European Commission 2007; Raad voor de Volksgezondheid en Zorg 2007), organized (OECD 2005), part of a system (Bolin et al. 2007), or being characterized by “functional specificity, achievement, universalism and being affectively neutral.” (Zadoroznyj 2009:271). Fourthly, implicitly, informal care is often presumed to take place at home, while formal care is presumed to take place in a care facility; and thus the location is taken as the basis of the formal- informal care distinction.

The main problem with all of these distinctions is that they focus on just one aspect of the formal-informal care dimension – payments, labour market, relationships or location – and implicitly exclude the other three themes, or presume these to follow the distinction made – e.g. paid care is then presumed to take place in an institution and non-paid care is presumed to take place at home. For our purposes these four ways of understanding the formal-informal dimension is too undifferentiated: the vulnerability of the care arrangements is not restricted to either the issue of money, labour market arrangement, the kind of relationships involved or the location: what makes care arrangements more or less vulnerable, is merely the combination of these four issues. As the common distinctions fail to include these four aspects, they neglect much potentially valuable information with regard to the *vulnerable* aspects of long-term care provision out of the picture.

Other concepts also prove to be inadequate for accurately describing the new care arrangements and assessing aspects that might contribute to their vulnerability. Concepts such as the *welfare mix* (see for example Powell & Barrientos 2004) and *de-familiazation* (Saraceno 2010) are useful for comparing welfare regimes at the *macro-level*, however they ignore characteristics of care-giving arrangements at the *micro-level* of households and families that can be crucial for assessing the factors that contribute to vulnerability.

Glucksmann and Lyon (2006, 2008) provide a useful framework for examining the inter-relationships between different sectors of society (family, market, public sector and civil society). But here as well, there is no structural attention for the different aspects of the resulting care arrangements at the micro-level.

2.1 Beyond the formal/informal distinction: a conceptual framework to assess the potential vulnerability of long-term care provision

The inadequacy of these frameworks for our purposes means that we need to develop our own conceptual framework. Our starting points are the micro-level approach employing the concepts of formal and informal care, and the observation that the characteristics of long-term care arrangements that used to coincide (such as paid care virtually always being professional care) have unraveled in many European countries (e.g. due to the introduction of cash-for-care schemes). The rise of the welfare state that took place during the 20th century and particularly after world war II, gave rise to a then rather new distinction between formal and informal care. However, since the 1980s, when the welfare state was attacked for being too costly and too paternalistic (Clare and Newman 1997) *the boundaries between formal and informal care have become increasingly blurred.*

In order to more accurately describe the changes in European long-term care at the micro-level, we have identified four aspects of formal and informal care that would typically coincide in the past, but seem to be disentangling nowadays, concerning, as was introduced above, *labour market arrangement, payments, relationship and location*. We focus on these four aspects as they draw attention to recent changes that might affect in one way or another the vulnerability of the contemporary modes of care provision for dependent individuals.

The first aspect that we take into account is the ***labour market*** arrangement, and with that the distinction between care being provided on the basis of an labour contract, either as an employee or a freelancer, or whether there is no such arrangement (even though care may be paid, e.g. by a personal budget).

The second aspect concerns the *relationship* between the care giver and care receiver, and concerns *professional* and *non-professional* care-giving. The criterion here is whether the care giver entered the relation as an employee of a professional care providing organization that is larger than only that single care-giver (and has not come about as the result of a pre-existing affective relationship, or as the result of social or legal obligations towards the care-dependent individual). Aspects such as the financial resources of the care organization, the availability of a sufficient number of professional care givers, and the normative expectations with respect to the emotional involvement, commitment and even self-sacrifice of carer givers, all influence the effect on the vulnerability of care provision.

As to the vulnerability of the care arrangement regarding the aspects of the labour market and the relationship aspect, two contradicting hypotheses can be defended:

1. *Professional care giving is less vulnerable than non-professional care giving, on the condition that there are sufficient public finances available, there is no labor shortage in LTC, and professionals are well-trained and qualified. Non-professional care-giving is valuable, but more vulnerable at the same time, in terms both of its instability (who replaces the caregiver if necessary?) and its potential lack of quality (who guarantees sufficient quality?).*
2. *Professional care giving is more vulnerable because these conditions are seldom met, and are moreover highly threatened with welfare state reform that is taking place today in countries with the most developed welfare states. Family members, partners and close friends are much more reliable over the course of people's lifetimes than the turbulent welfare arrangements with unpredictable regime changes, budget cuts and labor shortages.*

The third aspect concerns the issue of *payment*, and with that the distinction between *paid* and *unpaid* care-giving. The criterion here is whether the care-giver receives payment as a direct result of the care-giving. This second aspect clearly overlaps with the first, but it is important to distinguish the two. Other processes are likely to come into play for paid non-professionals as for professionals. Aspects that might influence the effects of assigning paid non-professionals an important role in long-term care provision might be the amount of payment, labor market factors, and normative (and sometimes legal)

expectations with regard to responsibilities for care for relatives and friends and with regard to market logics. Here again two hypotheses can be put forward:

1. *Overall, paid professional care-giving can be expected to be the least vulnerable provision compared to paid non-professional forms of care-giving, let alone unpaid non-professional care giving, the payment guaranteeing more stability and, in some circumstances, more quality as well).*
2. *Overall, unpaid care can be argued to be least vulnerable, the payment being being too vulnerable too regime changes, budget limits and budget cuts.*

The fourth distinction concerns the **location**: the distinction between *care at home* and *care in a care facility*. The criterion here is whether care is provided in a physical environment to which the dependent person has been moved for the purpose of receiving care from professional care-givers. Two hypotheses are often put forward:

1. *Overall, care provided in a facility decreases the vulnerability of care giving because of the constant proximity of professional care givers (so both in terms of stability as quality). When living in an institution, they are subject to procedures that guarantee a minimum of supervision and control, while at home neglect or abuse may happen and go unnoticed.*
2. *Overall, care provided in a facility increases the vulnerability of care giving because people generally feel more at home in their own homes than in as more impersonal institution. Moreover, when living at their own homes, they are treated with more respect than when they are institutionalized, in which case they run a much higher risk of being reduced to a 'case' or a number*

On the basis of these four distinctions, sixteen combinations of characteristics can be made (see appendix for all combinations). An explorative literature study has given us the impression that nine of these combinations accurately describe modes of care provision that do in fact exist within Europe. Our classification is visualized in the table below. For the sake of parsimony, we do not explicitly include the organizational aspect in this table. However, where two types are mentioned in one cell, the upper ones are the organized variant. In order to make the descriptions of the care arrangements more vivid, we have chosen to name the combination of the *non-professional, unpaid* and *organized* aspects of care arrangements *voluntary*. We describe the combination of the *independent* and the

non-professional aspect as care by *family or friends*. Lastly, the word *paid* is excluded from the description of *professional* care arrangements, since *professional* care is by definition *paid*.

	<i>Care in a facility</i>	<i>Care at home</i>
<i>Professional</i>	(1) Nursing (2) Freelance nursing	(3) Home nursing (4) Freelance home nursing
<i>Non-professional/ unpaid</i>	(5) Volunteers (6) Intimates	(8) Home volunteers (9) Home intimates
<i>Non-professional/ paid</i>		(7) Paid home intimates

- (1) Nursing = Organized care by professionals in a facility
- (2) Freelance nursing = Independent care by professionals in a facility
- (3) Home nursing = Organized care by professionals at home
- (4) Freelance home nursing = Independent care by professionals at home (often provided by migrant care workers)
- (5) Volunteers = Care by volunteers in a facility
- (6) Intimates = Care by unpaid family or friends in a facility
- (7) Paid home intimates = Care by paid family or friends at home
- (8) Home volunteers = Care by volunteers at home
- (9) Home-intimates = Care by unpaid family or friends at home

Each way that care is provided in reality can be classified in terms of these nine types. In many cases, care provision for a dependent person will be categorized not as one type of care arrangement, but as a combination of two or more types. For instance, a person may be cared for in a facility during the day (type 1) and at home by unpaid family members at night (type 9).

If certain types of care arrangements have grown in prominence in a given country, this is a good reason to evaluate the vulnerability of such modes of care provision relative to others. Aspects that logically seem to be influencing the vulnerability of care arrangements are the availability of different types of care givers, collective norms, the financial possibilities of the financer, and the labor market perspectives of potential care givers in a given country.

Combining the hypotheses expressed above, we can come up with two overarching contradicting hypotheses:

a There will be a hierarchy in vulnerability from type 1 to type 9: organized care by professionals in a facility is expected to be the most stable and of the highest quality whereas care by volunteers and unpaid family and friends at home is the least secure, in terms of stability and quality, or:

b There will be a hierarchy in vulnerability in the reverse order, from type 9 to type 1: organized care by professionals in a facility is expected to be the least stable and of the lowest quality whereas care by volunteers and unpaid family and friends at home is the most secure, in terms of stability and quality.

Of course, these are both very general statements, whereas the actual vulnerability (also) depends on various contextual factors (e.g. the traditions – ‘care cultures’- of a country). These hypotheses may nevertheless turn out to be helpful in order to better grasp aspects of vulnerabilities in a changing care landscape; vulnerabilities that often lead to all kind of inequalities.

3. Shifting responsibilities and the effects on inequalities

We will now turn to the second issue. This concerns the shifting responsibilities within long-term care systems, and the potential effects that these shifts have on inequalities among citizens. *We overall expect that transforming public responsibilities into private responsibilities increases inequalities among citizens, simply because some citizens have more skills and more social and economic resources to take care of themselves and their close-ones than others. And vice versa, shifting private responsibilities into public responsibilities is likely to have the opposite effect.* However, defining long term care as a private responsibility does not only have effects on those with a need for long-term care. It also affects inequalities among citizens in another way.

Margot Trappenburg (2009) explains the effects of defining long-term care as a private responsibility by describing the Dutch situation in which a system of “passive solidarity”, in which citizens pay taxes and social insurance contributions that the government in turn uses to provide collective goods and services, has increasingly been substituted by a

system of “active solidarity” that is characterized by the government’s normative expectation that “the average capable, physically and mentally healthy man or woman effectively provides help to older, less fit neighbors and colleagues.” (Trappenburg 2009: 7) Trappenburg subsequently describes the consequences of this system of active solidarity for “the average, healthy, tax- and social insurance contribution paying citizen.” (2009:11) She emphasizes that while in the old system of passive solidarity the burden of collective goods and services could, through taxes and social insurance contributions, be divided among citizens in a very subtle way that was thought to be fair, the system of active solidarity does not offer such possibilities. Instead, two other redistribution effects are inherent to the system of active solidarity.

First, compared to the old system of passive solidarity, the new system of active solidarity carries within it the danger of placing a disproportionately large burden on the shoulders of those that make the least money and have the lowest educational levels. She provides an example with regard to the resettling in the community of persons with intellectual disabilities and persons with psychiatric problems. In this process, two factors increase inequality among citizens. In the first place, limited public budgets often result in these persons being housed in the cheaper districts and definitely not in the best districts. This means that in practice, it are the residents of the cheaper neighborhoods that are expected to provide care to their neighbors. Trappenburg notes that even if this effect does not occur because governments are committed to spreading care dependent persons equally among districts, inequalities still grow because the leveling effects that progressive taxing used to achieve are made undone.

A second danger of active solidarity that Trappenburg describes is that it places a premium on antisocial attitudes. She argues that if governments ask citizens to take care of their dependent co-citizens, only a small group of citizens will answer this call. According to Trappenburg, these are always the same groups of people, and they are often groups that are already providing some type of care. The result is that the persons of good will are the ones that will be shouldering a disproportionately heavy burden for long-term care in a system of active solidarity (Trappenburg 2009: 11-16).

The effects that *shifts in responsibilities* have on *inequalities* among citizens, make them important to study. Therefore we examine the extent to which the responsibilities for

addressing the long-term care needs of dependent persons are shifting between the public, the market, civil society and individual citizens or families.

To answer this question, we need to more closely examine the responsibilities for long-term care. It is possible to distinguish between four different responsibilities. The *care provision responsibility* is that of actually *doing* the care work. In several countries, this provision of care is financed by another sector of society (e.g. families paying care givers who operate commercially on the market, or the state paying families to provide care); this sector then takes on the *financial responsibility*. Dividing these two responsibilities between different organizations produces a third kind of responsibility: the *arrangement responsibility*. This refers to the burden to arrange for a person or organization to take on the care provision responsibility. The fourth and last responsibility, which is taken up in a number of countries, is the *care support responsibility*. This refers to the provision of support for care-givers, such as training and support groups.

With regard to these responsibilities, it are not so much the legal responsibilities that are relevant, but rather who is in practice doing, arranging, financing or supporting the care provision.

Examining the division of responsibilities among sectors/people in different countries on the one hand, and inequalities with regard to the burden of care giving and with regard to access to care for dependent persons on the other, will help us to gain more insights in the precise relationship between these factors. We aim to find out how particular divisions of responsibilities affect the inequalities among groups of citizens. This knowledge can be used by policy makers to assess the likely effects of their current and future policies on inequalities among groups of citizens.

4. Popular experiences and expectations regarding long-term care

Now let us have a look at the third issue of this study. Here we look at the views of the European populations. The issues of vulnerabilities and inequalities are important, but we do not know when these are *experienced* as such by the general public. How do they feel about the contemporary organization of long-term care? And how do they feel about the developments that are currently taking place? In three ways we have tried to gain some insights in the extent to which the different European populations agree and disagree on

the current situations and developments. First of all, by examining whether groups of citizens who shoulder a disproportionately heavy burden for the provision of care, are defining their situation as problematic. Secondly, by examining which reform in long-term care has sparked the most debate or public resistance in their country. And a third method for discovering (potential) resistance to (future) developments in long-term care is to compare current normative expectations of governments with regard to the role of citizens in long-term care, to the normative expectations of citizens themselves. If the normative expectations of governments and citizens diverge, this represents a potential threat to the *quality* and *stability* of long-term care provision.

5. Methods

To study the above, we have explored existing country comparative literature about European long-term care, and we have sent out surveys to country experts. The literature study was conducted to form some first tentative impressions of the prominent modes of care provision in several European countries (The Netherlands, Germany, Greece, Italy, Norway, England, Sweden, Portugal and Poland), and the changes that have taken place over the past four decades. Subsequently, country experts (from all countries, except Portugal) have had a look at these first impressions. They have corrected them and added information to them. Furthermore, these country experts have answered a number of other questions that were relevant for our research. We will use the gathered information to compare the situations and developments in a number of European countries. Using our frameworks of care arrangements and of long-term care responsibilities, we will investigate which (past and current) tendencies can be found within the organization of European long-term care. Further, we will look at the consequences that these developments have (had) for the *vulnerability* of care provision to dependent persons, and for the *inequalities* between citizens. *Do the results corroborate our hypotheses?*

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Appendix

<i>Professional/ non- professional</i>	<i>Care in a facility / care at home</i>	<i>Paid/ unpaid</i>	<i>Organized/ independent</i>	<i>Care arrangement</i>
Professional	Care in a facility	Paid	Organized	1. Organized care by professionals in a facility
Professional	Care in a facility	Paid	Independent	2. Independent care by professionals in a facility
Professional	Care in a facility	Unpaid	Organized	DOES NOT EXIST
Professional	Care in a facility	Unpaid	Independent	DOES NOT EXIST
Professional	Care at home	Paid	Organized	3. Organized care by professionals at home
Professional	Care at home	Paid	Independent	4. Independent care by professionals at home
Professional	Care at home	Unpaid	Organized	DOES NOT EXIST
Professional	Care at home	Unpaid	Independent	DOES NOT EXIST
Non-professional	Care in a facility	Paid	Organized	DOES NOT EXIST
Non-professional	Care in a facility	Paid	Independent	DOES NOT EXIST
Non-professional	Care in a facility	Unpaid	Organized	5. Care by volunteers in a facility
Non-professional	Care in a facility	Unpaid	Independent	6. Care by unpaid family or friends in a facility
Non-professional	Care at home	Paid	Organized	DOES NOT EXIST
Non-professional	Care at home	Paid	Independent	7. Care by paid family or friends at home
Non-professional	Care at home	Unpaid	Organized	8. Care by volunteers at home
Non-professional	Care at home	Unpaid	Independent	9. Care by unpaid family or friends at home

Part II.

Country reports of: Greece, Italy, Germany, the Netherlands, England, Sweden and Norway

1) LONG-TERM CARE IN GREECE

** Country expert: Liz Mestheneos*

Current modes of care provision

Usually dependent persons receive care from **home intimates (9)**. Only in exceptional cases, when care by care from **home intimates (9)** is inadequate, does the state intervene (in the form of **nursing (1)** or **home nursing (3)**). However this is not possible in all municipalities. In two-thirds of all municipalities **home nursing (3)** is unavailable, in half no social-medical center (a form of **nursing (1)**) is available. Compared to other countries, the level of provision of these services is exceptionally low. The target group for these services is people with low income, without an informal network. People with higher than average incomes purchase **freelance home nursing (4)** on the market. However, hardly anyone receives **nursing (1)**, **freelance nursing (2)**, **home nursing (3)**, or **freelance home nursing (4)**.

Historical developments in long-term care

Until recently, hardly any public services were available and persons that were unable or unwilling to receive family support were largely dependent on the private sector or the Orthodox Church. **Nursing (1)** and **home nursing (3)** are now expanding.

Long-term care for different target groups

Long-term care for the elderly

Care giving by **home intimates (9)** is enforced by law and families usually fulfill their caring responsibilities. Some of this care can be regarded as care by **paid home intimates (7)**. Older persons often are part of an extensive family and kin network, usually receiving care in exchange for gifts and economic and practical support. If this network takes care of the elderly person it could be regarded as care by **paid home intimates (7)**. Also inheritance plays a role when people care for older persons and inherit their property in return. The role of inheritance is significant and could also be classified care by **paid home intimates (7)**.

The significance of professional care is unclear. While some statistics indicate that the percentage of elderly people receiving professional care is at most 8 percent (SCP 2007), in another report it is stated that “a very rough estimate might indicate that 27 percent of people in need of support receive it from foreign care workers” (Mestheneos et al. 2004, 20); this can in most cases be regarded as **freelance home nursing (4)**. The state and local governments focus provision of **home nursing (3)** on

socially isolated and economically deprived elderly that suffer from dependency. After discharge from a hospital **home nursing (3)** is provided.

In some municipalities **nursing (1)** during the day is available. The use of acute general hospital admissions (**nursing (1)**) for dependent older people is a widely recognized form of respite care.

Around-the-clock **nursing (1)** is uncommon. Less than 1 percent of people over 65 live in residential care. The public variant of this type of care is used by the oldest and most dependent part of the elderly population, and by those without family carers. Amongst the standard criteria for admission to public **nursing (1)** is the ability to be self-caring regarding personal care needs. The role of private sector **nursing (1)** is increasing. Income is the main criterion for admission to most private homes, with the degree of dependency affecting the price, as most homes charge extra for those requiring special or increasing levels of care.

If a dependent person is admitted to a hospital, care by **intimates (6)** is expected. In cases where this is not possible **freelance nursing (2)** should be arranged by the dependent person or his/her family to cover for the family.

If an older person is admitted to a hospital, there is usually a shortage of **nursing (1)**. Therefore it is necessary that care by **intimates (6)** is provided. Unpaid family members keep the older person company, make sure s/he is fed and do some nursing duties. If the family cannot provide this kind of care, they typically arrange **freelance nursing (2)** to cover for the family. This kind of care is often employed to cover for the family during the night.

Elderly care: historical developments

Nursing (1) has never played a large role in long-term care for older people. Public **home nursing (3)** services began developing on a pilot basis in mid-1980. Since then the provision of **home nursing (3)** and **nursing (1)** (in Open Care Centers) has been on the increase. The role of **freelance home nursing (4)** (often migrants) has been increasing since the early 1990s.

Recent developments are that day-time **nursing (1)** has become more important, that there is an increasing trend for public around-the-clock **nursing (1)** to be used by more highly dependent older people (who to a lesser extent have to be able to be self-caring regarding personal care needs), and that the role of private full-time **nursing (1)** is growing.

Critical issues and developments in Greek long-term care

Vulnerability of care provision

The inadequate provision of publicly funded support and care services (home or institutional) remains the main reason for insufficient care provision and the overburdening of non-professional carers. The overburdening of family carers has occurred with changing values e.g. the pressure for some women to enter or stay in the labour market; a smaller capacity to share care by siblings; a lack of financial resources for many – though the amount of migrant care workers in the homes of the dependent older person has increased.

The long-term care system has always been vulnerable – migrant care workers have relieved the pressure for those families or older people with money. Residential institutions remain more expensive than care at home with a migrant care worker (“professional”). The lack of private services also reflects that in terms of value migrants are far more stable in their caretaking than other caregivers, who work according to their private time schedules. No doubt this also happens in some neighbourhoods where a neighbour is given some cash to help periodically. This is an informal arrangement and has the benefit of being near at hand. But there is no data on this as is entirely unofficial – so even the dimensions are unknown.

Re-allocation of responsibilities

Concerning the care provision responsibility and financial responsibility there are no changing responsibilities.

As for *the arrangement responsibility*, there is some greater response of the Local Authorities for the vulnerable elderly without adequate family care and economic resources. However the funding of services remains problematic. This has traditionally been a family responsibility. Over the past four decades, there has been a somewhat greater response of the Local Authorities for the vulnerable elderly without adequate family care and economic resources. However, local governments do not always succeed in funding services.

As for *the care support responsibility*, this is mainly in the hands of the family – only with its absence does responsibility shift to the Local authority. Those with fewer economic resources take on more responsibility in the sense that they cannot pay for private help. This also coincides with educational levels. However in all social classes, even if personal or domestic care is not actually done by the family member, they still bear all the responsibility for arranging, managing and supervising caring arrangements – and often also pay for it. Over 80 percent of **unpaid family care at home (9)** is done by women. Men mainly provide spouse care.

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2) LONG-TERM CARE IN ITALY

** Country expert: Barbara Da Roit*

Current modes of care provision

Care by **(paid) home intimates (7 and 9)** represents the first response to care needs. In principle care by home intimates has traditionally been **unpaid (9)**, even if this does not mean that monetary concerns do not enter care relationships (inheritance and so on). With the introduction of care allowances family care has not been explicitly “monetized” in most cases, in the sense that cash benefits were not meant to be an explicit means of paying for family care. However it is known that cash benefits are partly passed on to caregiving relatives. This is not based on working contracts and the like, but more on informal arrangements between parents and children, between siblings and so on. Only some local care allowances have introduced the idea of a caregiving contract, remunerated by the local cash allowance.

According to qualitative research, families tend to manage on their own “as long as possible”. Only then they opt for paid care. And also in this case paid care and family care are usually combined (for instance family members provide direct care when the paid caregiver is absent during weekends and so on). What “as long as possible” means varies a lot. In general, the decision to employ a paid carer is linked to the belief that the older person needs someone to be around all the time. In many cases this reflects a very high degree of dependency (there is evidence of a positive correlation between degree of dependency and use of paid care), but in some cases paid care is also used to reassure the relatives, also in presence of a lower degree of dependency.

Next to and in combination with family care privately paid care (delivered by migrant caregivers, as **freelance home nursing (4)**, above all represents a relevant response. There is evidence that this type of care is widespread not only among high income groups, but also among (lower) middle classes. Carers are often living with the dependant person and providing round-the-clock and extremely flexible care. Private care is widely accessible due to its relatively low costs (thanks to limited regulation, underground economy and undocumented migration) and to the presence of cash allowances (namely a national flat-rate benefit) that reduces the financial burden on families. The use of this form of private care is particularly important among older people living alone (even if their non-co-resident relatives maintain an important role in providing and coordinating care).

Home nursing (3) is little developed and does not represent a considerable care resource (despite territorial differences). **Nursing (1)** is considered as a last resort in relation to different factors: limited availability, high costs for the final users and their families, stigmatization.

Historical developments in long-term care

Policy-wise there has never been and there is still no consistent long-term care policy in the country.

Interventions for the disabled adults (mainly within the framework of work inability) were traditionally categorical and cash based (national disability pensions and allowances). Until the late 1970s no explicit policy for the disabled elderly was enacted.

The end of the 1970s represents a turning point in policy development due to the devolution of the competence in the field of care and social assistance to regions and local authorities. In general there was a debate about the development of home care and territorial services (as opposed to institutions) for dependent people. However, the limited funding of social services and the dispersed competences prevented a comprehensive home and territorial care system from developing. Even if care services are more developed in northern regions, they remained marginal also here. In all long-term care remained a family responsibility, also from a formal point of view. Social care is not a social right and relatives have extensive obligations towards the dependants.

Care allowances in the domain of long-term care developed in two ways. First, they emerged as a development of the traditional cash-based policies in the field of disability. In the early 1980s a new national cash allowance was introduced, first intended for the adult disabled and subsequently extended to the elderly. The allowance (*indennità di accompagnamento*) is a flat-rate non-mean-tested benefit directed to people that are evaluated totally dependent *and* are in need of constant care (a bit less than 500 euro per month in 2010). The beneficiaries are allowed to use the benefit freely, with no need to justify their expenses. Second, in relation with the debate on freedom of choice, empowerment of the users etc., in the late 1990s and early 2000s several regions and local authorities introduced new and diverse cash allowances, mostly directed to the elderly dependent. These new instruments are territorially dispersed and limited in coverage (as well as generally means tested and quite low), however.

The debate on long-term care has not produced a systematic reform of the system. Recently some regions have initiated a reform of the sector, whose consequences cannot be assessed yet.

In practice, the most important transformation in care practices is not a direct consequence of (missed) policy reforms but rather consisted in the rise of the private care market as described above. This transformation took place since the late 1990s and can be considered as a mass phenomenon. The emergence of this new care arrangement is linked on the one hand to the increasing demand of care, the availability of monetary resources and of relatively cheap migrant labour (originally from South America and subsequently from Easter Europe).

Long-term care for different target groups

Long-term care for the elderly

The typical responses are the ones described above. The care market is particularly developed among the frail elderly. In general the debate about long-term care in the last few years has been a debate mainly about the frail elderly. The national care allowance (which was initially meant for the disabled adults only) was extended to the frail elderly in the mid 1980s. Due to epidemiological reasons and to the ageing of the population, the elderly are currently the most important target group. More recent regional and local care allowances have the elderly as the main target group, even if the coverage rate and the generosity of these allowances remain very limited.

The rise of the care market at the end of the 1990s was above all concentrated among the frail elderly.

With respect to older people with dementia, there is no general policy. Local and regional projects may address the specific needs of this population (for instance by providing specific care units within care institutions). However, due to the limited development of these special projects, older people with dementia are either cared for in regular units within institutions or at home. It is worth underlining that, according to qualitative studies, dementia (particularly when associated to behavioral problems) is generally considered “a good reason” for institutionalization among the relatives of older dependent people.

Long-term care for individuals with physical disabilities

The most important support for the disabled adults consists of national monetary transfers (mean-tested disability pensions and a non-mean-tested care allowance).

Also for this target group territorial services are limited and only complement the mainly family-based care. Given the fact that disabled adults, differently from the elderly, live more often with other family members, there seems to be a more limited use of paid care.

Disability pensions have developed in a categorical way (distinct pensions for people with hearing, speaking and sight impairment) and in relation to the inability to work (disability pensions *strictu sensu*). Territorial services have developed, similarly to the case of the elderly, in the 1980s and 1990s to a limited extent and according to different regional and local patterns.

Long-term care for individuals with psychiatric problems

The deinstitutionalisation movement of the 1970s has concerned mainly psychiatric patients. However, the closure of institutions has generally not meant the development of adequate territorial services. The latter do exist, but leave the bulk of the care to the families.

Critical issues and developments in Italian long-term care

Vulnerability of care provision

The limited availability of care services has been a constant aspect of the Italian care system. Despite some growth over the years, it has never reached a sufficient level. Home care services do not only reach a small part of the population in need, but they also provide limited support (in terms of number of hours of help per week). Residential care is also little developed (circa 2 percent of the population aged 65+ is the national average), and it is also expensive for the users. The diminishing availability of care by **home intimates (7)** is a newer phenomenon, which is due to both socio-demographic factors and to changes in family relation and care practices.

Due to the limited availability of **(home) nursing (1 and 3)** care has traditionally been provided solely by the family. As a result, the overburdening of **(paid) home intimates (7 and 9)** has traditionally been the most frequent cause of immediate insufficient care provision.

Over the past decades, increasingly the unavailability of sufficient family care, as a result of both socio-demographic factors and changes in family relation and care

practices, has become another important factor that leads to immediate insufficient care provision.

The most immediate cause of insufficient or bad quality care provision are low personal or family resources: care, money and other competences. Low care resources in the family means that no one is available to care, low money resources means that paying for care is a problem, low competences means that arranging the care (provided by paid carers mostly) is a problem: people do not know where to look for a carer, how to check on her (or him), what to expect and so on.

The overburdening of family carers has traditionally been the most frequent immediate cause of insufficient care provision. And that more recently the absence of family carers (because families have become smaller, family members live further apart, women are more active in the labor market) is becoming an important cause of immediate insufficient care provision to dependent persons, plus the fact that in many cases caregivers are potentially there, but they do not perform the direct care they would have in the past (because they have an alternative: paid care). In any case, all this leads to insufficient caregiving in the form of informal caregiving, but not necessarily insufficient caregiving as such (as paid care substitutes for the informal part).

The development of the care market was not linked to the transfer of responsibility from the state (social policy, society, etc.) to the individuals and families. By contrast, there was a shift from a family-based system to a mix of family and market. If vulnerability was in the past to be found among family members of dependent people (who were expected and obliged to care) and among care dependent people without a family, it is now shared by care dependent people, family members and migrant care workers.

Re-allocation of responsibilities

The care, financial, arrangement and care support, provision responsibility all remained within the family. The family however, increasingly tends to “externalise” the provision of care to paid carers. And the national cash allowance, introduced in the 1980s, represented a contribution to the familial financial responsibility.

Groups that have more responsibilities are typically middle-age daughters of dependent older people, and parents of disabled (adult) children. Migrant care workers (mostly middle aged women from South American and Eastern European Countries) take up care in case the family externalises responsibilities.

Tensions between governments' and citizens' normative expectations

The introduction of the new regional and local care allowances have attracted a lot of attention. Ideological standpoints (in favour or against choice, market forces etc.) have prevailed in the debate for and against these interventions, without considering their limited impact on the system.

There has been very strong resistance against a national structural reform of the sector (which should imply a reform of the national care allowance!). At the national level the debate has concentrated mostly on migration issues: long-term care policies have been look mainly as a migration-related problem due to the importance of migrant care workers in the sector. Two mass regularization of undocumented

migrants (2003 and 2009) and the *quota* of migrant care workers within the migration flows regulation were consensual decisions.

At the regional and local level, the main concern has become “how to regulate private care and include it in the local care system”. In other words, the migrant care model has become an accepted model that needs to be “regulated” in order to reduce its contradictions and problems.

3. LONG-TERM CARE IN POLAND

* *Country expert: Piotr Bledowski*

Current modes of care provision

In general, long-term care in Poland is not considered a public, but rather a private responsibility. **Home intimates (9)** are primarily responsible for caring for a dependent (grand-) child, (grand-) parent or partner. Only if one does not have a family, one can apply to community health institutions, which provide **home nursing (3)**. In case of severe care need, there is a limited amount of institutional care or **nursing (1)**. There is also a vivid grey market of migrant care workers, working as **freelance home nurses (4)** and mostly come from Ukraine and Romania. This partly substitutes the drain of better educated Polish **nurses (1-4)**, going to Western European countries such as the Netherlands and Germany to receive better pay. **Volunteer care (5 and 8)** is not well developed in Poland, in a European comparison; especially younger people do not feel the moral obligation to perform voluntary care tasks outside their families.

Historical developments in long-term care

In Poland, only 20 years ago, after the transition to a democratic regime, social policies were developed. Two major reforms aimed at providing social assistance and reforming the educational system. Long-term care was not a first priority of the state, and as a result not one clear policy aiming at long-term care exists. Instead, long-term care programs are dispersed among different Acts, such as social assistance and the general health care fund. Additionally, there are many private community initiatives, which are sometimes (partially) supported by the state. Only recently, voices were heard to restructure health care and develop a long-term care policy. In 2010, Bledowski et al. presented a 'green book' to the government in place with the title: "Long-term care in Poland: description, diagnosis, recommendations", which basically forms the beginning of a public discussion about long-term care in Poland.

Long-term care for different target groups

Long-term care for the elderly

According to Polish customs, members of the family members are responsible for the care of a disabled elderly person. There is a common expectation that the family is capable of caring for its seniors and there is a socially sanctioned moral obligation to care for one's parents. In general, it is a very frequent situation that various members of the family do certain things for each other (e.g. the grandfather takes care of the grandchildren, while his daughter prepares meals for him and helps him with the household). As a result, care received by dependent elderly people consists almost entirely of care by **home intimates (9)**. 92 percent of the elderly say that in case of sickness, they can count on the help of their families. The strong family ties often result in elderly people and their family living together in one home. In rural communities,

neighbors and friends support family carers. This help is often occasional and usually results from a temporary need to replace a member of the family.

Family carers do not receive any direct financial benefits from the public. However, some forms of care can be regarded as care by **paid home intimates (7)**. Retirement, pension or nursing benefits (the latter are received by all persons above 75, but are too low to pay for even the most basic nursing care) are often an important source of income for extended families, which they cannot do without. As a result, caring for the elderly is often a service granted in exchange for financial help in supporting the household. Another way of 'payment' is inheritance of a house after the elderly person has passed away, in exchange for care giving during his/her dependency. A last form of care by **paid home intimates (7)** is neighbors receiving a small payment from the Social Welfare Center for helping the elderly with their household. However, this option is not usually used. In larger communities, family members can receive temporary help from volunteers (e.g. in the form of 'granny sitting'). However, the availability of **home volunteers (8)** is relatively limited.

There is no legally determined level of dependency that that gives elderly the right to help from the state. According to the law, the state is responsible for the care over citizens in extreme social and economic situations. This obligation is never denied, but is restricted by the economic situation. The need for non-medical services (such as transport, helping in contacts with the environment, supplying food, help around the household) usually exceeds its availability. Public **home nursing (3)** is means-tested. Help is directed first of all to those who have no possibility of receiving similar help from their families, and who are unable to manage their household, take care of personal hygiene, and/or live an independent life and have social contacts. Dependent on the needs of a person, benefits may include help in managing the household (doing shopping, keeping the house clean, help with preparing meals etc.), help in maintaining personal hygiene (washing, bathing), and help to provide social contacts by mobilizing the community. Time devoted to performing these services is dependent on a persons needs. This is usually no more than two hours, two to three times a week. The access to **home nursing (3)** is very varied. It is generally easier to get in cities than in the country. In case of prolonged sickness nursing care can be granted by the district nurse. However, it has a temporary character or consists of instructions on providing care and controlling the quality of care provided by the family. Especially in the cities, a private care market is beginning to develop. Because of the high prices, the demand for these services is usually lower than the supply, but the demand for nursing and care taking services is rather unfulfilled. Because the public cannot provide **home nursing (3)** throughout the whole day, families are often forced to purchase private (**freelance**) **home nursing (3 or 4)**. Because of the limited financial capabilities of the elderly, using the services of private care givers happens only in critical situations. In families with higher incomes, illegal or temporary care givers are sometimes hired, usually for a few hours per day.

Most publicly provided long-term care is **nursing (1)**. Lower income groups make use of care services that are provided in social welfare centers. However, there is little state provision of these kinds of services, especially in rural areas. One form of **nursing (1)** is the geriatric day care units, in which a few hours of care to elderly is provided during the day. This kind of care is combined with care by **home intimates (9)** in the afternoons and during the nights. Day care homes are usually available for four to

eight hours a day. Elderly can get a warm meal, take part in rehabilitation exercises, are cared for by a nurse and have access to various other forms of organized activity. The elderly using these services are usually quite fit, because most of the homes have no way of providing transport. Qualification for these kinds of units is mainly based on an assessment of social conditions. However, the number of public day care homes is small. There is hardly any sheltered housing in Poland. There are care homes however. The decision whether to admit a person to a care home is taken by the local authorities on the basis of an environmental enquiry and the opinion of a physician. One of the criteria for admittance is loss of fitness (need for nursing care in a specialized institution, which is impossible to provide at home) or a detriment in social conditions (loneliness, lack of family lack of ability to manage the household, very low income etc.). Residential homes are for less disabled older people who are not in need of any special social care or nursing. Nursing care homes are available for those people who require nursing and constant attention, and are beyond the possibilities of hospital treatment. Few people receive around-the-clock **nursing (1)**, 1.7 percent of the elderly (unspecified) receive this type of care. There are too few nursing beds to satisfy the demand. There is no custom of care by **intimates (6)** in a facility when a person is receiving **nursing (1)**.

Historical developments

Poland has traditionally relied on care by **home intimates (9)** for the elderly. The proportion of people receiving **nursing (1)** has always been low. Day time **nursing (1)** (day care) is relatively new, but their number is already getting smaller. Care by **home volunteers (8)** has been developing only in recent years.

Long-term care for people with intellectual disabilities and psychiatric problems

Long-term care for people with intellectual disabilities and psychiatric problems is relatively well-established. Institutions that provide specialized around-the clock **nursing (1)** for intellectually disabled persons exist. There are different reasons for that. As for people with intellectual disabilities (an estimated group of 400.000 persons), they were care for specifically during the time of transition from communist to democratic rule. For this group, the transition, and the subsequent institutional changes, was difficult to comprehend, and they were specifically targeted with aid to reorganize their care arrangements.

As for psychiatric patients, their need was secured by in particular, possibly related to the background in the psychiatric sector of a previous Health Minister who underlined the need for professional and long-term aid. It is therefore possible to use **(home) nursing (3-4)** in addition to care by **home intimates**.

Long-term care for people with physical disabilities

Care for disabled persons staying at home is almost entirely unpaid care by **home intimates (9)**. Social assistance provides **(home) nursing (1 or 3)** for families with low income and care of disabled people. However there is little provision of community care services and there are not enough nursing beds. Receiving **(home) nursing (1 or 3)** in smaller towns and rural areas is problematic. In larger cities, a private care market is

providing **(home) nursing (3 and 4)**, which include services such as help with cleaning, shopping, meals-on-wheels.

Critical issues and developments in Polish long-term care

Vulnerability of care provision

The vulnerability of Polish care provision is mainly due to the lack of alternatives if the family falls short of long-term care, and particularly, as in the near future more older people will need institutional care in general. The state leans too easily on family care, which may have been possible in the context of high women unemployment rates and young population, but which will certainly be under pressure if trends such as increasing women's labor participation and an ageing society will also set foot in Poland.

Apart from the sustainability of care provision, a related concern is the quality of the long-term care services, which is under pressure due to lack of training and recognition of professional carers. (Freelance) professional carers earn a very minimal wage, which cause an emigration flow of carers to Western-Europe. As a sending country, Poland receives migrant carers from other Eastern European carers, who are even more low-skilled and cheaper; thereby replace displacing the care provision problem.

Re-allocation of responsibilities

The *care provision responsibility* remains in the hands of the families; in particular the women and children. In Poland, unemployment amongst women is relatively high at the moment, and therefore, they have more time to provide for family care than under communist rule, where they had to combine care and work. Families also hold the main *financial responsibility* for care giving, yet the state and workforce also contribute via community health care funds and social assistance. In the case of social assistance, a user-pay-principle applies, and only the health care fund supplies publicly financed care, mostly in institutions, or to a smaller extent in the community. The *arrangement responsibility* is that of families, the pressure to live close to your home intimates is therefore high. And if e.g. elderly do not have family in their proximity, they can rely on the community for the arrangement of care. The *care support responsibility* has not yet developed in Poland; there are no programs that specifically support family carers, migrant carers and so on.

Tensions between governments' and citizens' normative expectations

Currently, the development of a secure long-term care fund is not high on the agenda of the Polish government. Rather, the pension system and employment security programs are the object of policymakers. However, with the envisioned growth of the amount of elderly (growing towards 6 million in the coming years) the plea for a sound long-term care system will be more urgent than before. To develop a long-term care system alike the Western European design, particularly the social solidarity between young and old needs to grow. At the current moment, young Polish citizens do not see the need to spend 2 percent of their wage on a fund they might have to rely on 60 years from now. In that perspective, young Polish citizens and the Polish government are very much in line with their thinking. On the contrary, people who have dependent elderly in their families,

especially in rural areas, have experienced the difficulty of providing for a dependent family member, and are rather willing to invest in national health care if that frees them from their caring duties.

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4) LONG-TERM CARE IN GERMANY

* *Country expert: Hildegard Theobald*

Current modes of care provision

Typical arrangements include care within the family context, mainly without professional (**freelance/home**) **nursing (1-4)** or **paid home intimate care (7)**. More professional home-based care provision depends on the level of dependency; people categorized as having a higher dependency more easily receive professional home-care, and potentially also move into a nursing home, most often being elderly women providing **nursing (1)**.

Historical developments in long-term care

Important developments include the introduction of the Long-term Care Insurance, the introduction of cash payments and universal coverage for it, and the expansion of professional home based care.

Long-term care for different target groups

Long-term care for the elderly

A dependent older person typically receives care by **paid home intimates (9)** in the early stages of dependency. If a dependent person has deficits in carrying out at least two basic, and additional instrumental, activities of daily living for an expected period of at least six months, than one is eligible for Long-Term Care Insurance (LTCI) benefits. At this point, the dependent person can choose to receive **home nursing (3)**, or s/he can choose to use the benefits to arrange care from **paid home intimates (7)**. The latter is by far the most common choice and this choice. Only 9 percent of beneficiaries of cash benefits use it to buy services privately, it is mainly used within the family framework or wider networks as a symbolic acknowledgement for the vast amount of care work provided.

In Germany there are no co-payments for home help and basic nursing. The Long-term Care Insurance grants a lump sum for service use dependent on the level of care dependency. You can use this lump sum and purchase services up to the limit without any co-payments. However, the granted services are not sufficient. If you want to have a sufficient home-based care provision you have either to buy and pay privately further services, to ask for informal, family support or it can be granted further public support after a means-test within the framework of social assistance (Social statutes (SGB) XII). Financial difficulties are caused not by high co-payments but by the uncovered needs due to principle of basic funding. It is a problem of socio-economic class related to a high care burden for informal carers for the lower socio-economic classes. It is also related to the living situation. Living alone and simultaneously limited informal support is related to high private costs and eventually to a limited care service provision.

This is partly motivated by the financial burden that results from opting for **home nursing (3)**, because the lump sum for service use that is granted by the LTCI is too low to purchase sufficient **home nursing (3)**. This also means that if the minority, which does choose to purchase **home nursing (3)**, wants to receive sufficient care at home, they have

to privately buy and pay for additional services. It can be related to services provided by organization and to grey market care or support with household services, but it is not independent professional care. Some can be granted further public support after a means-test within the framework of social assistance (3). It is also related to the living situation. Living alone and simultaneously limited informal support is related to high private costs and eventually to a limited care service provision.

Moreover, in some regions – mainly in rural areas – day time **nursing (1)**, such as day care centers, is insufficiently available. Home nursing (3) is sufficiently available, but this care is restricted to the more nursing-technical activities for people that are in the least severe of the three categories of dependency. Due to the limited lump-sum typically beneficiaries choose the more nursing-technical activities, but you could also choose household services. If you choose household services, you have no public support left for (basic) nursing activities. In contrast, specialist nursing activities are not a part of the long-term care package paid by the Long-term Care Insurance but are granted within the framework of the Health Insurance. In reality, people in need of homecare are typically dependent on unpaid care by home intimates (9).

The choice to move to a care facility is typically made if an elderly person lives alone and lacks sufficient (**paid**) **home intimates (7 and 9)**. Moving to a care facility implies receiving mainly **nursing (1)**. However, **volunteers (5)** and **intimates (6)** tend to play a modest role as well. The size of the facilities providing **nursing (1)** is typically quite large: 19 percent of the facilities had 1-20 places, 28 percent had 21-50 places, 35 percent had 51-100 places; 19 percent had more than 101 places (however, these statistics were collected in 1999, and therefore might be outdated). The percentage of elderly people using sheltered housing is low, relative to other countries.

If a person has been receiving around-the-clock **nursing (1)** after acute illness such as a stroke, geriatric day clinics allow the transition of returning to one's own home. People that use this kind of day-time **nursing (1)** are typically over 80 years old and are classified as dependency category 1 or 2. Persons who are continually confined to bed are excluded from day care, whereas short-term need for bed rest is not a problem.

Elderly care: historical developments

Nursing (1), supplemented by **volunteers (5)** and **intimates (6)**, have for a long time played an important role in Germany. At the same time, for family members of those elderly living at home, there was a strong moral obligation, as well as a legal obligation; to provide unpaid care at home, as **home intimates (9)**.

Since the introduction of the Long-Term Care Insurance in 1995, dependent older people have increasingly been receiving around-the-clock **nursing (1)**. Also, care at home has more often been **home nursing (3)** (the number of people receiving home-help was steeply reduced, but the number receiving home nursing more strongly increased) and even more often care by **paid home intimates (7)**. Home help and basic nursing care (bodily care) are granted within the framework of the Long-term Care Insurance based on the principles of universalism and basic funding. Within the framework of the Long-term-Care Insurance beneficiaries mainly choose basic nursing care (= bodily care) see above. In recent years, elderly people increasingly use **home nursing (3)** instead of care **by paid home intimates (7)**. Thus, there has been an increase of professional care at home, but the families often provide care mainly without professional support. Despite

this there has been a change with regard to the rationales related to informal care provision (see above, part 1).

Since 1995, the number of places in geriatric day care increased sharply. Available statistics indicate an expansion from 3 178 places in 1993, to 23 000 places in 1998, and an expansion of 104 percent between 1997 and 2000.

The traditionally large role of **volunteers (5)** and **home volunteers (8)** is under threat since the late 1980s. It has proven to be increasingly difficult to attract volunteers. There are strategies to allocate voluntary workers to home-based and residential care work. Even the Pflegeleistungsergänzungsgesetz (Complementary Nursing Act) of 2002 actively involves voluntary workers into care provision.

Long-term care for people with intellectual and physical disabilities

The different schemes already named are also available in case of disability (Long-term Care Insurance SGB XI, Health Care Insurance SGB V, Social Assistance SGB XII). Furthermore, in general, the eligibility criteria, regulations etc. are also valid in case of disability with the exemption of the Social Assistance scheme (SGB XII), which in a situation of disability is providing universal benefits without means-testing. The Federal Law on Rehabilitation and Participation of Disabled People (SGB IX), which came into effect in 2001, provides the framework for the establishment of a care arrangement and thus the integration of the different schemes. The law aims to “enhance self-determination and participation in society on equal terms for disabled respectively people at risk to become disabled.” As eligibility criteria are defined “Physical, cognitive impairment or mental health problems, which last more than six months (or can be expected to last more than six months) and which do not correspond to age-related behaviour.”

With regard to home-based care, the benefits of the different schemes are used to create a comprehensive care arrangement with the municipalities responsible for care/case management services. In 2004, on a basis of model projects and in 2008 permanently a personal budget was introduced related to an individual social right. As one mode of integration it aims to establish an integrated home-based care provision based on the benefits of the different schemes. The personal budget is typically granted as a regulated cash benefit and can be used to purchase services but also to employ a personal assistant. In an individual contract, activities and goals of the support, the proof/record of the use of benefits, the (regular) working-contract between the care users and the personal assistant, quality assurance measures etc. are defined precisely. The employer duties can be transferred to organisations. Evaluations of the model projects show that mainly benefits of the Social Assistance scheme (SGB XII) and the Long-term Care Insurance (SGB XI) are used to finance the home-based care arrangement. The level of support differs widely with an average level of support of 1000 € per month. Different forms of needs assessments have been established on a regional level.

Long-term care for people with psychiatric problems

Due to the emphasis on physical disability within the framework of the Long-term Care Insurance it is more difficult to develop a sufficient care arrangement for these groups in case the problems are typical for the age-groups. Public support for not-age-related problems, see above.

- 1) With the Complementary Nursing Act in 2002 a small benefit has been introduced to provide specific support for people with psychological disabilities and above all dementia illness. The amount has increased with the last reform in 2008.
- 2) Home-based psychiatric care provision can be granted within the framework of the Health Insurance Fund.

Critical issues and developments in German long-term care

Vulnerability of care provision

The vulnerability of the care system consists of the overburdening of non-professional care givers and absence of professional **(home/freelance) nursing (1-4)**. This is due to emphasis on informal family care. Societal changes that have increased vulnerability include an increase of long-term care needs and a decline of care by **(home) intimates (6 and 9)**. The changing situation has only partially been compensated by the increasing public support since the 1990s. The situation differs related to socio-economic class and living situation.

Re-allocation of responsibilities

Concerning the *care provision responsibility*; the family still delivers the main bulk of care provision. There has been an inroad of men, above all older men- husbands - but even younger men= sons since the 1990s. There has also been an increase of professional care provision. Professional care provision has traditionally been provided by non-profit private providers. This has changed, now approx. 50 percent of professional care is provided by private for-profit providers.

Second, concerning the *financial responsibility*, the Long-term Care Insurance provides public economic support, but still there are private costs, mainly related to institutionalised care. Many beneficiaries try to avoid private costs related to professional home care by limiting their service use.

Before the introduction of the Long-term Care Insurance care provision was almost only privately financed. In 1962 a means-tested system of public support has been introduced within the Social Assistance framework (today SGB XII). Since the end of the 1980s some care situations were covered by the health insurance funds (SGBV).

Since the 1970s, when only means-tested public support was available, the financial responsibility has shifted more and more from the family towards the public. Since the end of the 1980s some care situations have been covered by the health insurance funds, and this shift towards the public has been reinforced by the introduction of the LTCI in 1995. However, the family still partly bears the financial responsibility.

Third, the *arrangement responsibility*: Since the 1970s, the arrangement responsibility is mainly taken over by the families or the beneficiaries themselves. With the last reform in 2008 a social right related to care management and advisory has been introduced. Now all beneficiaries or potential beneficiaries can get advice up to case management services in specific local offices (Pflegestützpunkte) without any charges.

In 1962, within the framework of the Federal Law of Social Assistance, regulations were established to grant support related to long-term care (home-based, institutionalised) or household services after a means-test. Within the framework mainly the local offices were responsible for the arrangement related to home-based care. It is

different with regard to institutionalised care. Due to the high costs the elderly were often impoverished, i.e. only after a certain time-period in the nursing homes they needed public support. The arrangements were already their.

Within the framework of the LTCI even before 2008 the beneficiaries/their families could get information without any charges by the insurance funds, local offices or care providers. The care dependent or their families choose the care provider themselves. In reality, often the families established the care arrangement.

Fourth, concerning the *care support responsibility*, this is mainly in hands of the non-profit private sector. But also some regulations within the framework of the Long-term Care Insurance support informal carers. Yes, training is regulated within the law. Support groups are often established by civil society organisations.

Tensions between governments' and citizens' normative expectations

In Germany, there is a vivid debate on the support of beneficiaries with dementia illness. Researchers, civil society organisations (e.g. Alzheimer society) put forward that elderly with dementia illness are disadvantaged in the system due to the orientation towards physical impairments, and demand for a change in the regulations. In 2002, the Complementary Nursing Act was introduced, to arrange for additional support for people with dementia illness and in 2008 it was even further extended. This 2008 amendment includes a proposal for a new assessment instrument which include more criteria/difficulties related to dementia illness.

Second, the mode of funding of LTC is also object of continuous debate. Proposals to make LTC sustainable in the future consist of two lines of arguments. On the one hand, left-wing parties advocate the introduction of a *Bürgerversicherung*, i.e. all citizens are insured within one insurance respectively redistribution between private and social insurances. Background of the proposal are the deficits of the social insurances and the surplus of the private insurances due to the more healthy, less frail people insured in private insurances. On the other hand, right-wing parties want to establish an additional pillar based on a capital-funding within the social insurances to fill the gap.

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APPENDIX I: Entitlements to long-term care in Germany

Entitlement to claim LTCI benefits is based on deficits in carrying out at least two basic, and additional instrumental, activities of daily living (ADLs and IADLs) for an expected period of at least six months. These activities are:

- washing, showering, bathing, tooth brushing, combing hair, shaving, using the toilet;
- cutting meals, eating/drinking;
- going to bed / getting up, (un)dressing, standing, walking, climbing stairs, leaving and entering the flat (ADLs), and;
- shopping, preparing meals, cleaning rooms, doing the dishes, changing and washing clothes or heating (IADLs)

Dependent people only qualify for benefits if certain time requirements for the required help are met. Respective minimum and maximum thresholds are 90-180 minutes per day (grade I), 180-300 minutes per day (grade II), more than 300 minutes per day (grade III) – based on the productivity of an average informal carer. (Rothgang 2003, 30-31).

5) LONG-TERM CARE IN THE NETHERLANDS

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** See also “The embrace of responsibility: citizenship and the governance of social care in the Dutch Social Support Act (WMO)” by Evelien Tonkens, Loes Verplanke, Jan Willem Duyvendak and Thomas Kampen in this programme book

Current modes of care provision

Access to publicly funded care

Access to publicly funded care is one of the cornerstones of the Dutch welfare state. The Dutch law (Exceptional Medical Expenses Act/AWBZ, 1986) that ensures that people with intellectual and physical disabilities, psychiatric problems and frail elderly can receive care at home or, and in case of severe disabilities and old age, in an institution. The amount of hours as well as the kind of care one is entitled to is decided by a central office on the basis of written description of the care needs of the patient and oral information of their general practitioner.

Dutch long term care clients make use of public services, which are for the most part delivered by private organisations. Only a fraction of the population, particularly frail elderly well off, makes use of private care homes where one has to pay a substantial amount of money in exchange for more hours of care and a more luxurious environment with more privacy. But even in those situations, the same public money that goes into the public services is paid by public funding here: the luxury is extra, on top of the basic level.

But recently, a new law has entered the scene, the Social Support Act (WMO, 2007) in which care provision is a task for local governments, and in which there hardly any universal claims, except for the claim that the local government needs to compensate disabled people and frail elderly for barriers to participation that their disability may cause them. For example, one can be entitled to receive transport to important locations, although this will generally be a shared taxi or minibus than a taxi for oneself.

Choice

Choice is another cornerstone of the system. Once the central office, CIZ (central eligibility office) decided that one is entitled to receive care, patients can opt of a personal budget and arrange the care oneself, or chose an organisation from which the services are taken. As marketization entered long term care since roughly a decade, one can chose between various competing providers.

Informal care

The amount of time that is spent on informal care by family members or other intimates outdoes formal care with a factor seven, it was calculated in the beginning of this century. Compared to the use of child care services, the use of long term care services are much accepted and less gendered: one is not considered to be a bad daughter or mother when one's parents or disabled children make use of these services for a substantial

amount of time, contrary to the informal limit on the use of child care of two or three days a week.

Care by **home intimates (9)** and to a smaller extent **home volunteers (8)** and **paid home intimates (7)** are forms of informal care that long term care dependents rely on, and which is now even more stimulated within the WMO.

Allocation system

National guidelines exist for eligibility when it comes to AWBZ, since care under the banner of the AWBZ concerns legal entitlements. Care provided under the SSA is not phrased in terms of legal rights: here what clients can claim, depends on the budgets of a municipality and the guidelines that the municipality framed, and the availability of informal care. And, as various researches have shown, in both the AWBZ and the SSA, it also depends on the degree to which one is eloquent, stubborn and self-assured enough to protest against an entitlement that one considers to be too low.

To complicate things even further, a third party is involved in care arrangement and care provision: next to the AWBZ and the SSA, there is also a role for the health care insurance companies.

Over the last years, eligibility has been reduced in order to cut costs or rather restrain the rise of costs. This has both been done by directly tightening eligibility rules in the AWBZ, and by moving services from the AWBZ to the SSA.

Care in place?

For those who live at home but are entitled to receive care on the basis of the AWBZ or the SSA, **home nursing (3)**, **freelance home nursing (4)** are available, both by way of a personal budget and by direct service provision by an organisation. In addition, there are day care services for a few days a week, depending again on the amount and kind of care one is entitled to. There is a negative perspective on nursing homes, but much less so on other kinds of institutional care.

Historical developments in long term care

Universal access was arranged in 1968 with the AWBZ, the law that ensured people with intellectual and physical disabilities, psychiatric problems as well as frail dependent elderly a place in an institution. All expenses were paid for then. During the 1970s and 1980s there was a huge rise in the use of long term care, particularly in institutions. But ironically, by the late 1960, just when universal rights for intramural care was settled, a mounting wave of criticism on the institution could be witnessed, starting with criticism on psychiatric institutions in the vein of the anti-psychiatric literature and movement, and spreading onto the care for people with intellectual disabilities and to a much lesser degree also elderly care.

From the early 1990s this criticism was adopted by policy makers, not the least because of the rising costs and the idea that care at home would be much cheaper. In a short period of time, the tide changed: now, policy makers advocated for living at home as the best option for virtually everyone with care needs.

Developments in informal care

This turn from the institution to home care of course came with higher demands from **home intimates (8)** and **home volunteers (9)**. At first this demand was implicit, but from the turn of the century local and central governments explicitly put informal care on the agenda: they tried to find out how much was actually provided and by whom, and to stimulate people to provide informal care at home in any form.

According to a prognosis made by the Netherlands Institute for Social Research (2007), informal care is not at stake in the near future, as the amount of people giving care to relatives and friends will grow from 370.000 to 380.000 persons between 2006 and 2020. Concerning the characteristics of informal caretakers, there will be two changes; first, in the group of persons aged 75 or older, more people will perform informal care work, and also more men will provide informal care in the near future, for example for their partner (De Boer 2007).

A relatively recent development is that, via the personal budget (PGB) people with a long term care need can hire **paid home intimates (7)** to provide the care work. In the Netherlands, even close relatives can be paid, after a budget has been supplied (although the regulations have become increasingly tightened). In the Netherlands there are circa 84.000 **paid home intimates (7)**, which amounts to 5 percent of the total amount of informal caregivers (Knijn et al. 2009).

Long-term care for different target groups

Long-term care for the elderly

Elderly care went through a process of professionalization since the 1950s, in order to 'free' the elderly from dependence on their families. As a consequence, Dutch elderly care is largely de-familialised (Da Roit 2010). Two phases can be discerned. During the 1950s and 1960s, the aim was to institutionalize elderly care. Care homes or so-called 'verzorgingshuizen' offers packaged care for elderly. Next to care homes, there were also nursing homes, which mirrored general hospitals: people were supposed to enter a nursing home when seriously ill and more or less condemned to stay in bed. However, this hospital life could go on for a long time; today people stay in nursing homes for 1 to 2 years on average.

From the 1980s onwards, the ideal of a care homes and nursing homes was criticized as isolating and medicalising, together with most other intramural arrangements. The new goal became deinstitutionalization and supported living, in order to enhance the autonomy and the social inclusion of elderly by continuing their lives in their own homes as long as possible. Today, to enter a care home or a nursing home, one has to be seriously disabled, otherwise one has to stay at home and receive home nursing or help from home intimates or home volunteers.

Loneliness is a prominent problem among the elderly. Upcoming are policies that combine independent living with care ('woonzorgcentrum'); and provide a mild form of sheltered living, where elderly can buy an apartment in a flat for seniors while engaging in social activities with elderly flat mates (or volunteers). Care homes are to be dissolved or transformed to nursing homes. Only if the elderly become severely disabled or ill, will they be entitled to a place in a nursing home ('verpleeghuis'), which again focuses on the terminal phase of life, as was the original idea of a nursing home.

Long-term care for people with a physical disability

People with a physical disability have typically been served by care organizations since their rights were installed in the Exceptional Medical Expenses Act (AWBZ) in the 1968. Physically disabled people have always been very well represented in client and patient boards, being also for a great part responsible for the advancement of the Personal Budget (PGB) in the 90s. The Personal Budget is very popular amongst those with a physical disability, as care can be tailored to the individual needs. Although the physically disabled have firm social rights to receive public aid, care or physically disabled is not de-familialised. Most typically, physically disabled persons receive a mix of professional and informal care at home, but recent welfare reforms stress the importance of family care responsibilities.

Long-term care people with intellectual disabilities

Since 1968 care for people with intellectual disabilities is provided and funded through the Exceptional Medical Expenses Act (AWBZ), along with the nursing and care sector and the mental health care services. In 2008 almost 150,000 people in the Netherlands were entitled to AWBZ-funded care in the basis of their intellectual disability. Care is mostly provided by care organisations; it consists of living support, day care and support in finding employment or leisure activities. Eligibility for these care arrangements requires a valid indication by the needs Assessment Centre (CIZ). The CIZ distinguishes several care categories: long-term residential care; short-term residential care, day care, support and treatment (including personal care and nursing). As with other groups, the dominant ideal is to live at home and prevent institutionalization.

Intellectual disabilities: historical developments

Care for people with intellectual disabilities has a long history of care by home intimated as well as by charitable institutions, in which all kinds of people with care needs or people who suffered from social exclusion (such as unwed mothers) were placed. A child with a mental disability was a source of shame for parents, as it was considered a punishment from God or at least a sign of a lack of civilization. This changed with medicalisation of intellectual disabilities in the late 1940s and 1950s. As medical causes of disabilities were discovered, the shame for parents was reduced. This stimulated parents to tell their stories of the pains (and sometimes joys) of having a disabled child, which further boosted their emancipation and that of their children. Medical and psychological help was possible, but this could only take place in an institution, as only here the necessary knowledge and skills for treatment could be found. As a result, the institution emancipated from a sad and awkward place to be avoided, to the best place to be in order to be treated and maybe even cured.

However, ironically, the moment as these rights to be institutionalised were firmly rooted in the AWBZ, in 1968, massive criticism of life in the institution bursted out, inspired by the anti-psychiatric movement and anti-institutional theorists like Ervin Goffman. Also, the medical promises concerning cures crumbled down and with them, one of the pillars of the merit of living in an institution.

Since the 1980s, the dominant policy ideal is deinstitutionalisation for people with intellectual disabilities as well as psychiatric patients. In practice, the growth of institutions continued, but from the late 1980s the ideal of deinstitutionalization was also

put into practice. Clients were stimulated to be autonomous and independent, and the institution was not considered the right place to practice autonomy. Today, autonomy is still the dominant ideal, but a range of settings and forms of care and support exists.

Long term care for people with psychiatric problems

Concerning institutionalization, the trajectories of care for people with intellectual disabilities and for people with psychiatric problems roughly converged: the history of (de)institutionalization described above is more or less similar for people with psychiatric problems. A difference between these sectors concerns the ways they are organized and financed. Mental health care is divided into a curative and a non-curative part: the curative part is embedded in the regime of general health care law, for which insurance companies are responsible, while the non-curative part is embedded in the AWBZ and the SSA. This has created a lot of complexities and transferral between these two regimes, e.g. when a patient was treated for less than a year, it was an issue for the Health Insurance Law, while the second year he was delegated to the regime of the AWBZ. Today, the rule is that all mental health care that takes more than a year, in an intramural setting, is part of the AWBZ. All other mental health care is considered curative and falls under the heading of the health insurance law.

Critical issues and developments in Dutch long-term care

Vulnerability of care provision

As should be clear from the brief historical sketch above, long term care provision has gained a solid place in the Dutch welfare state. Rights are quite well developed and there is a rich array of service provision. However, various developments put this solidity under pressure.

Firstly, the sheer complexity of the system, with simultaneous responsibilities and constant shifts concerning the rules, regulations and responsibilities of central government and insurance companies (in the AWBZ) and local governments (with the SSA) impedes the accessibility. This is particularly the case for people who do not possess the necessary bureaucratic skills and knowledge of the system, such as lower educated people and migrants. So even though there may be, on paper, various kinds of services that one is entitled to, in practice it is often not easy to receive these, as it is not always clear where to go to, whom to ask and how and where to complain if necessary.

Secondly, there is a constant discussion of 'cost explosion' and the need to restrain costs. As a consequence, there are constant efforts, particularly by central government, to reduce costs, mostly by reallocating responsibilities to local government, as will be discussed below. Efforts of cost reduction are not very successful, however: over the last decades there has been a constant rise in the costs of long term care. This of course can at least be partly explained by ageing and thus a rising amount of elderly people in need of care services.

Thirdly, as the need of cost reduction is almost uncontested, but costs nevertheless continue to rise, there is also a continuous debate on the need to increase efficiency and to reduce bureaucracy. It is often argued that organizations lack efficiency and are thus themselves to be blamed for rising costs: if only they would be more efficient, cost would be contained. Others argue that the well meant demand for efficiency is

counterproductive as it tends to result in higher standards in accountability and thus tend to increase bureaucracy.

Division of care labour

Reallocation of responsibilities from the central government (AWBZ) and to local governments (SSA) and comes with a reduction of entitlements: as the AWBZ is framed in terms of individual legally enforceable rights, while the SSA is framed in terms of provisions. With the SSA there is a fixed budget, and the degree to which people receive services depends on the available budget. The only real entitlement in the SSA is the right to be compensated for restrictions to participate in society on account of one's disability; it is not yet clear what this really means in practice.

Re-allocation of responsibilities

Long term care, both paid and unpaid, is predominantly performed by women. In nursing, the predominance of women is highest - over 90 percent - concerning the elderly and people with intellectual disabilities, and somewhat lower in the area of mental health care. Even though the issue of a lack of personnel in the foreseeable future pops up regularly, the gender dimension is hardly an object of debate, neither in policy circles nor in public debate. The idea that men would enter nursing on a bigger scale is implicitly considered not realistic, even though a bigger supply of personnel is urgently called for. It is implicitly assumed that (migrant) women will fill the gap, or that informal carers will do so.

Informal carers, however, are also predominantly women. Home intimates are sometimes men, particularly husbands who care for their frail elderly partners. The pressure on women to provide informal care, leads to serious problems of overburdening. Particularly among migrant groups – both Muslims and migrants of other backgrounds - , the pressure on women is often very high, as even the idea of discussing task division is already considered a threat to female identity: good women simply perform their duty, without even talking about it.

Tensions between governments' and citizen's expectations

Long term care is an issue that is highly debated in the media and politics. Particularly during the first decennium of this century, news items showing poor quality popped up every now and then, mainly concerning elderly care, sometimes also care for people with intellectual disabilities. The quality of elderly care, with special attention for nursing homes, has been taken up by many political parties but most of all by the populist anti-immigrant party, that frames it as a choice between allowing more immigrants to enter the country, or taking good care of 'our' elderly who built up this country. Over the last years, some measures in nursing homes alleviated the pressure a bit; this may explain why the issue of quality in elderly care is a bit less prominent now.

Care for people with intellectual disabilities or psychiatric problems is a less constant theme in the media; it only pops up around occasion personal tragedies, such as, recently. The story of Brian who is caught in chains a substantial part of the day. This evokes a lot of public anger but the anger dies down as quickly as it pop up, without much measures being taken. In the case of Brian, it sufficed when the Inspectorate

argued that the treatment did not fail but that people like Brian are very difficult to handle and that sometimes there is no other way than putting them in chains.

Concerning people with psychiatric problems, another highly debated issue is isolation. A few years ago, it was concluded that too many people were put in isolation cells to many hours of the day, which resulted in quite successful projects all over the country to reduce this.

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6) LONG TERM CARE IN ENGLAND

** Country experts: Caroline Glendinning and Sue Yeandle*

Current modes of care provision

Access to publicly-funded care

Informal/family care is undoubtedly the first, and remains the most common source of care. Resource constraints have raised the eligibility threshold for publicly-funded care to, in many instances, substantial or critical levels. In assessing potential needs for publicly-funded care, any help given by informal/family carers is taken into account and does not count towards eligibility for publicly-funded care.

Increasingly, once someone is assessed as eligible for publicly-funded social care, the level of resources they are given is determined by a formulaic resource allocation system (RAS). This has the potential to allocate similar levels of resources to people with similar levels of need (albeit that the total budgets available to different groups of service users vary – both between user groups and between local authorities), in contrast to resources that are allocated by giving people services.

Choice in publicly-funded care

Current policy in England is to offer these resources in the form of a personal budget. It is important to note that a personal budget does not have to be taken in the form of a cash direct payment; it can be held by the local authority care manager; by a third party such as a carer or a trust; or given to a service provider who supplies services as and when requested by the budget-holder. Considerable flexibility in the use of personal budgets is advocated, with people increasingly using them to purchase ‘ordinary’ services – taxis, help from friends, equipment, holidays, as well as to employ personal assistants and purchase domestic and personal care.

Informal care

Although family members are not responsible for long-term care by law, some contribution on their part is normal practice. These contributions are part of a normative arrangement within the family. People are not pressured into doing this by social services. This contribution in the form of care by **home intimates (9)** is part of the assessment of the need for **(home) nursing (1 and 3)** by the local government. Practice of taking in the wishes of carers in assessing care needs is variable between local authorities; in some authorities carers may not even be asked about whether they wish to continue providing care or about the support that they may need in order to continue doing so. This is despite local authorities’ statutory duties to assess the needs of carers, including their aspirations/desires in relation to employment, training and leisure activities.

Allocation system

On behalf of equal accessibility of care, national guidelines for eligibility exist (see appendix I). However, the effect on uniformity is limited, since assessment is executed by the local government. The local government is responsible for awarding publicly financed care, but has a limited budget for long-term care. This means that in practice the

local governments tend to award care to the most urgent cases. The local resources (which are dependent on the national resources and a Resource Allocation System) determine the volume of publicly financed (**home nursing (1 and 3)**). To be eligible for services your care needs have to be substantial or critical in most municipalities. The large majority of municipalities no longer provide care for people with moderate needs. And in some municipalities only critical cases are supported. This means that in many cases where there is a moderate care need, no care is available. This means that all the needs of this person have to be satisfied by either privately purchased care (so-called 'self funding clients'), care by **home intimates (9)** or that people manage without care.

For persons that are assessed eligible for **home nursing (3)**, the option of receiving Direct Payment instead of publicly arranged care is made increasingly attractive. This is partly to discourage reliance on formal professional care, such as special day care centers, which are increasingly closed down. The money received can be used to pay for **home nursing (3)** or **freelance home nursing (4)** or to arrange care by **paid home intimates (7)**. The budget for Direct Payment is the same as the net costs of services assessed as required, as determined by the Resource Allocation System (RAS). Relatives can be paid with this money, provided that they do not live together. Assessed *nursing* care needs, cannot be translated into Direct Payment. The reason is that nursing care is free under the National Health Service (NHS), so in principle people are never requested to pay for this. The government has also given local councils the power to give Direct Payments (DPs) to carers to meet their own assessed needs. The act excludes from the definition of a carer volunteers from a voluntary organization and professionals. However, the take up of Direct Payments remains small.

Care in place?

To enable people to remain living in their own home, part-time **nursing (1)** in the form of day care is available. If a person is assessed as being eligible for around-the-clock **nursing (1)**, s/he can choose to remain in his/her own home as long as the costs for **home nursing (3)** don't exceed the costs for intramural care. The trend has been to emphasize that people should be supported to remain at home for as long as possible and for as long as they wish to. There is a negative perspective on care in a facility; therefore people will only choose this when there are no other options: when they or their carers feel they can no longer cope at home.

Historical developments in long-term care

The 80s: from institutionalization to community care

In 1984 the introduction of social security funding enabled a shift in ownership from local authority to private sector. There was an increase in admissions to residential and nursing homes because this care was funded by the social security budget; people were often admitted before they really needed it (see Balloch, 2007:21). At the same time, there was a lack of investment in services to support people (particularly people with moderate to high support needs) at home.

This would indicate that in this period dependent people would receive **nursing (1)** in an earlier stage than before. However, there were exceptions, as Balloch (2007, 22) also states that the 1980s and 1990s were characterized by a shift to care in group homes,

mainly for people with learning disabilities and mental health problems. Balloch (2007) reports a decline in the total number of people receiving around-the-clock **nursing (1)** of 13.3 percent between 1991 and 2001 in England.

The 90s and 00s: ageing in place

In the mid-1990s, the strategy of keeping more people in their own homes has gone hand in hand with the intensification of services, a trend especially visible in elderly care. This was needed to keep the very frail and vulnerable at home. The number of hours of **home nursing (3)** increased substantially (+14 percent between 1999 and 2002; +21 percent between 2000 and 2004), but at the same time the number of households receiving services rapidly decreased (-23 percent between 1999 and 2002; -11 percent between 2000 and 2004). So although the volume of home care increased, it was generally made available at a later stage. This has resulted in a larger role for **home intimates (9)** in earlier stages, and a smaller role in later stages. Also some people have purchased private (**freelance**) **home nursing (3 and 4)**. The targeting of publicly funded **home nursing (3)** on the most dependent persons has continued and currently some local authorities have begun to restrict adult social services to people with 'critical' needs.

Home nursing (3) today focuses very much on personal care, whereas in earlier stages these services would have provided house cleaning, shopping and other similar services. The availability of Direct Payments (DPs) has only led to a modest increase in care by **paid home intimates (7)**, since take up of this new provision has been limited.

In England DPs were legislated for in the Community Care and Direct Payments Act 1996 and from 2000 the DP scheme was available to people aged 65+ (Community Care (Direct Payments) Amendment Regulations, 2000). It was further extended (in 2001) to include carers, parents of disabled children and 16-17 year olds. The total number of people receiving DPs, initially very small, has been rising - from 37,000 in 2005-6 to 67,000 in 2007-8. This represented 2.5 percent of all clients receiving community-based services in 2005-6, and 4.4 percent in 2007-8. 15,000 people aged 75+ (2.9 per cent of all clients of this age) received DPs in 2007-8. DPs put those cared for in control of the funding available to support them; many users of DPs employ their own personal assistants and care workers. Take-up figures nevertheless show that, despite emphasis on the development of this policy, the proportion of clients, especially older clients, using DPs remains small relative to the total population of service users. However there is a clear shift to emphasizing personalized care as an aspiration. And the shift towards focusing on personal care has resulted in people often taking up Direct Payment to use it for arranging a wide range of care tasks.

Developments in informal care

Since the 1970s **home intimates (9)** have become more important in supplying long-term care, because of demographic developments (an increasing number of care dependent people). Because more people have been staying in their own homes longer, the total number of people receiving **nursing (1)** has remained at about the same level. As a consequence, the volume of unpaid family care may also have increased because older people tend to be supported at home until they are much more frail and dependent – they are admitted much later to residential care than in the 1980s. For other groups, admission to residential care is very rare (and only for the most severely (intellectually) disabled

people). But when people are admitted to residential care, in most cases only those with critical needs, the service provision has become more intensive for this smaller group (thereby possibly relieving informal care duties).

Developments with regard to the Carers Allowance

A Carers Allowance is intended to support family carers and only claimed by a small minority. It is important to note that the carers allowance is only part of a package of policy and support for informal carers. This package is quite broad in comparison with other countries and consists of: i) rights to an assessment of their own needs, ii) possibility of receiving support from the local authority (usually in the form of a period of respite care or a grant to be spent on equipment or a break), iii) groups and services run by voluntary organizations, iv) the right to request (but not the right to receive) flexible working arrangements, and v) protection of contributions for the state pension during periods out of the labour market while caring.

Carers Allowance: The history of Carer's Allowance was summarised in the House of Commons Work and Pensions Committee's 2008 report 'Valuing and Supporting Carers':

'Until April 2003, Carer's Allowance was known as Invalid Care Allowance (ICA). ICA was introduced in November 1975, following the 1974 White Paper, Social Security Provision for Chronically Sick and Disabled People. It was - and still is - the principal social security benefit for individuals looking after chronically sick, disabled and older people in England, Scotland and Wales. It was intended to be an income replacement benefit, and reflected the fact that it was considered important that those who provided care should have an income of their own rather than be financially dependent on the person being cared for. An important element of the original intention was to protect carers' pension entitlements, and the new benefit facilitated this protection through National Insurance credits. It was introduced with a range of other new non-contributory benefits, all of which were set at 60 per cent of contributory long-term benefit rates.'

'When first introduced, ICA was available to men and single women of working age who were no longer 'breadwinners' because they had given up paid employment to care for at least 35 hours per week for a disabled person in receipt of Attendance Allowance (a benefit not payable until the disability had lasted for six months). In addition, eligibility criteria were such that the care recipient had to be a close relative; however in 1981, availability was extended to individuals caring for distant kin and friends. Initially married and cohabiting women, as well as certain categories of unmarried women (not considered breadwinners) were excluded from claiming the benefit, even if they too had quit work to care; however ICA was extended to include married women in 1986.'

'ICA was renamed Carer's Allowance in 2003. Amendments to Section 70 of the Social Security Contributions and Benefits Act 1992, that came into effect on 28 October 2002, allowed carers aged 65 and over to claim the benefit, and extended entitlement for up to eight weeks following the death of the care recipient.'

The then Department of Social Security commissioned research into the targeting and effectiveness of ICA in the late 1980s. (This) identified (that)..: 'eligibility criteria were complex; the nature and level of care provided by claimants had adverse implications for

their independence, social and employment activities; the majority of carers reported additional expenditure related to disability and caring; a substantial proportion of claimants had been affected by overlapping benefit regulations; very few carers had heard about ICA when they began to provide high levels of care; and take-up of the benefit appeared to have been very low prior to 1986 (reflecting the publicity about ICA's extension to married women)'. The report author recommended: 'increasing its value, and permitting higher levels of earnings from part-time work in combination with receipt of ICA - issues that are still current and have been argued for powerfully by contributors to the present inquiry.' (WPC 2008: 35-37)

Worth also noting that:

Since 2003, Carer Allowance (CA) has been available to carers who are:

- 16 years old or over
- caring for 35 or more hours per week for a person who is in receipt of Disability Living Allowance, Attendance Allowance or Constant Attendance Allowance.

CA claimants are allowed to earn up to £100 (2010-11 rate) from paid employment without losing any of their CA (Directgov, 2010a), and must not be in full-time education (more than 21 hours of supervised study a week).

The latest figures on CA (November 2009) indicate that there were 969,710 carers eligible to claim CA, of whom 646,900 were women and 322,810 were men. Of these, approximately 527,000 were actually paid the Allowance - the rest had an 'underlying entitlement to CA, but because they received other state benefits or pensions which were higher, were not actually paid any money in respect of CA (because of 'overlapping benefits rules'.

Long-term care for different target groups

Long-term care for the elderly

Most long-term care for the elderly is provided by **home intimates (9)**. Care by **Home intimates (9)** is usually not provided by co-habiting relatives but by relatives that live in the same town, and by relatives that live further away and visit on the weekends.

However, although this kind of care is the most important source of care for dependent older people overall, it is not for the most dependent. The more severely dependent people are, the greater the chance that they receive **home nursing (3)** in addition or as a substitute for informal care.

Regarding day care use (including social and recreational activities), it is reported that 32 percent of people aged between 65-74 attend some form of daily **nursing (1)**, with the figure being 29 percent or persons aged 85 and over. The proportion living in sheltered housing and similar projects like supported housing or extra care housing (municipalities are experimenting with these kinds of projects, resulting in a wide range of housing types), which can be regarded as around-the-clock **nursing (1)**, increases with age from 3 percent of the persons aged 65 to 69, to 19 percent aged 85 and over.

The significance of Direct Payment for the group of older persons is low. Less than 5 percent of the population aged over 65 receives it. However, some forms of payment to non-professionals for care do seem to play a role. Persons aged over 65 who have needed care at home for at least six months, are awarded an Attendance Allowance that the older person can spend as one likes. The attendance allowance was originally intended to compensate for some of the extra costs of disability. It is frequently taken into account in local authority assessments of the means-tested charges/contributions that users must pay towards their services. As such, it is essentially an inter-departmental transfer, from one government budget to another.

Low-income non-professional care-givers that care over 35 hours a week for a person receiving an Attendance Allowance are awarded a Carers Allowance. This carer allowance is meant as a benefit to compensate for lost income as a result of care giving activities and is care by **paid home intimates (7)** and the Attendance Allowance is likely to have this same function. However it is only available to people who make less than about hundred pounds a week (not on average: you cannot make more than 100 pounds in one week). For this reason, the Carer Allowance cannot be combined with a state pension.

Care by **(home) volunteers (5 and/or 8)** plays a minor but significant role. This form of care usually comes into play when people receive **(home) nursing (1 and/or 3)** since most voluntary care takes place within organizations that also employ a considerable paid staff.

Elderly care: historical developments

Since the 1980s, long-stay hospital provision has declined and residential care and nursing home care provision shifted from public to private ownership. Also, several types of sheltered housing were introduced. Sheltered housing on the whole does not have care staff on the premises; a new development, 'extra-care' housing, provides much more intensive personal and domestic care, in a private housing setting. Thus, there is a small but significant volume of care that is provided in housing settings, which can be regarded as around-the-clock **nursing (1)**.

Many changes were introduced in the early 1990s however, when the NHS and Community Care Act was passed. Elderly people were to be cared for in the community instead of in institutional environments. This kind of care provision was often combined with day-time **nursing (1)** in the form of day care, often in combination with **home nursing (3)** and/or **home intimates (9)**. Yet, the move away from around-the-clock **nursing (1)** has been modest. The proportion of elderly people using these kinds of facilities seems to not have decreased very much in the late 1990s and early 2000s. In 2001, intermediate care has been introduced: a new 'layer' of care to prevent unnecessary hospital admission, support early discharge and reduce/delay long-term residential care. The number of places for this form of short-term **nursing (1)** is still growing. This form of care was introduced to prevent people from going straight from hospital admission into a long-term care facility. In this type of care they are prepared to go back to living in their own home.

Many changes did take place with regard to **home nursing (3)**. According to Pavolini and Ranci (2008: 252) the percentage of elderly receiving public **home nursing (3)** has

fallen from 8 percent to 4 percent over the last 15 years. Comas-Herrera and Wittenberg (2003) reported that this decrease took place between 1994 and 1998, mainly affecting people with moderate care needs. This means that **home nursing (3)** for elderly persons has increasingly been focused on those with most severe and critical care needs.

Long-term care for people with intellectual disabilities

Though it is still a minority, a larger part of this group is using Direct Payment than in the case of the elderly. Direct Payment is made available to ensure that persons with intellectual disabilities can live independently or in shared housing, and can lead socially inclusive lives. Currently a DP is presented to a person with intellectual disabilities requesting publicly-funded aid as the dominant option.

There are two typical points for transitioning to **nursing (1)**. The goal is to support young persons with learning disabilities to live independently. Therefore, with persons from this group plans are often made to transfer to independent living or a shared home with a social worker in support. A second point for transitioning to a facility is when the informal caretaker, i.e. parents of an adult person with learning disabilities becoming dependent on long-term care themselves, for instance because of old age. In this case a plan is made to satisfy both the parents' and the child's needs (also as carers).

Intellectual disabilities: historical developments

With the 1959 Mental Health Act, a broad policy of desegregating the mentally disordered and reintegrating them into the community was introduced. Before the 1970s, people with intellectual disabilities were relocated from large institutions into smaller (but still sizable) hostels in towns and cities and day care centers for children were introduced. By the 1970s, around-the-clock **nursing (1)** began to be replaced by provisions such as day-time **nursing (1)** and **home nursing (3)**. The role of **home intimates (9)** grew. However, in the 1970s still limited movement took place.

Long-term care for people with physical disabilities

People with a need for physical disability care who are over 16 and under 65, have a limited capital and get at least £320 worth of support a week or £16,640 a year from social services, if they are eligible for the Independent Living Fund. The Independent Living Fund, that funds the cash payments for people with a physical disability, was founded in 1988. Eligibility for ILF funding is increasingly restrictive and is now (or soon will be) limited to people who are in paid employment.

Physically disabled persons can receive discretionary cash payments to purchase **home nursing (3)**, **freelance home nursing (4)** or care by **paid home intimates (7)**. Relatives, however, can not be employed with these cash payments if they co-habitate.

Long-term care for people with psychiatric problems

Since 1954, when the number of patients in public institutions reached its peak (148.000), people with psychiatric care needs have increasingly been brought back into the community. By 1974 there were 60.000 fewer persons using large-scale around-the-clock **nursing (1)**. However, the creation of community care services did not keep up with de-institutionalization, resulting in a larger role for care by **home intimates (9)**. This situation remained the same at least until the mid-1980s.

Critical issues and developments in English long-term care

Vulnerability of care provision

By examining the vulnerability of the care provision, we look at factors that can cause immediate insufficient care provision. The main issues in England are:

Underfunding. There is increasing concern about the sustainability of available funding as the population of older people grows. It is widely acknowledged that current arrangements are unsustainable. And moreover, because of shortages of sufficient professional care givers, services experience problems to deliver enough good quality care.

Inequity. Eligibility criteria and levels of provision vary between local authority areas. The lack of resources at the local level leads to rationing/targeting of provision. This results in the most serious cases receiving care, but persons with 'moderate' care needs are often not provided with care.

Unfairness. Some people have to sell houses and spend down their assets if they happen to need residential/nursing home care. Furthermore, even when people are eligible for care, people sometimes do not know how to find and arrange care on the care market.

In retrospect, care has become very different over this period of time. Some aspects have become better: recognition of individual choice and needs by social workers. But there are no additional resources to pay for these improved policies, so there is a crisis in funding. The local authorities are unable to collect sufficient money to fund the new plans. As a result, less serious cases do not receive care anymore.

Re-allocation of responsibilities

Undoubtedly the total volume of care has increased – mainly because of demographic shifts and the increase in numbers of very elderly people; but also because of advances in medical techniques and technology that enable people with very severe disabilities to survive and live at home. It is likely that more families are providing more intensive care than previously – but this cannot be proven by any empirical data.

First, concerning the care *provision responsibility*, informal care is officially voluntary, but tends to be taken into account in assessments of eligibility for local authority-funded care. As a result, we might consider part of informal care as obligatory, as formal care is not provided as a substitute for informal care. Also, the market has also been given a major responsibility in the provision of care. There have been a lot of private investments in residential homes, and increasingly in domiciliary care. Local authorities purchase care from home care agencies under contracts. The state has taken responsibility for regulation and setting the standards; both home care agencies and residential homes are now subject to strict registration requirements. This has put severe pressure on the sector and restricts the flexibility and responsiveness of home care services.

There is a strong trend from local authorities that provide care themselves towards local authorities contracting care on the market. A few local authorities do not provide any care themselves anymore. However, most local authorities still have some type of own provision. This is often intermediate care (for support after hospital) and very

intensive short-term support. Intermediate care is usually provided in health settings – community hospitals, nursing homes etc. Intermediate care usually involves intensive physiotherapy and occupational therapy to improve physical functioning. Increasingly local authorities provide home care reablement for the first few weeks after referral for home care support. Reablement aims to improve confidence and self-care skills. In both reablement and intermediate care, provision of equipment is very important.

Second, the *financial responsibility* for care is mainly in the hands of the local authorities. The better-off pay a supplementary charge which differs per local authority. There is an assets test so that everyone with assets of more than £23,000 (including the value of a house) must pay for their own care till they have spent down to that level and become eligible for local authority-funded support. In addition, charges based on a test of income are required. This is true for residential care, domiciliary services and personal budgets (the budget-holder will be required to contribute their own resources towards the total budget). Levels of means-tested user charges vary between local authorities.

Third, concerning the *arrangement responsibility*: because of the strict assessment criteria, there is a substantial (but unknown) number of people who fund their own care because they are not eligible for local authority funded support. Of those who are eligible, most people opt for public care which is purchased on the market by the local authority, which as a result carries the main responsibility for arranging care.

Fourth, local authorities have the legal obligation to establish the care needs of informal carers and respond to those, and thus have the care *support responsibility*. Informal carers have a right to a carer's assessment. Local authorities assess what the needs of the carers are. If a carer wants to remain employed, the local authorities have to support the carer in a way that allows him/her to remain employed. This could be through services like respite care or through arranging home care. In addition, the central government has set up a national help line, and a free program for support, to learn carers how to manage their caring role. Furthermore, charities also take on responsibilities in providing support. 'Carers UK' offers training and a help line. The Princess Royal Trust for Carers has a network of centers that are given grants by the local authorities to provide services for carers. Crossroads arranges respite care. So there is a strong voluntary sector that is working in cooperation with the local authorities. And all local authorities receive annual grant allocation (the Carer's Grant) that they have to spend on carer support.

Division of care labour

Women take on more care than men. 62 percent of care is provided by women. However, men are increasingly getting involved because of changes in family structure and in geographical distribution of families (other relatives often live far away). The main reason for the increasing number of male carers is demographic – as the population ages, increasing numbers of men become carers for their spouses/partners. Men carers outnumber women in the 65-74 age group. In the care work force the overrepresentation of women is stronger.

Persons from the lower classes provide more care. They give up their jobs earlier in order to care, and they can't afford to purchase care on the market. However the class difference is not huge. Especially Asian groups provide more care because there is a

greater need for care in those communities, as a result of poor health. These inequalities are not often voiced by these groups.

Overall, the increasingly high thresholds of eligibility for local authority-funded support means that the burden of funding and providing care has increased on all citizens.

Tensions between governments' and citizens' normative expectations

Concerning access to care, persons from the middle class are better able to find out what they are entitled to and how to get it. Persons from ethnic minorities, especially if they don't speak English, do not receive the care that they are entitled to. Rich persons are able to purchase care if they do not yet qualify for publicly paid care.

Concerning normative ideas for care, most people view care as a normal part of life. There is widespread agreement that caring is a normal part of life, among the public and among political parties. People think that caring for parents is something you have to do. However, carers do think that they should be supported in this, in a way that enables them to continue living the rest of their life. This is also the aspiration of the government, driven by a pragmatic view: with the increase of people needing care, they are not going to find enough care workers. Yet in practice, only a small minority of employers has carer-friendly policies, regardless of carers' rights to request flexible working.

In England, the main ongoing LTC debate is about funding: how to balance financial resources with growing use of the collective care system? Everybody agrees that something has to be done about the inadequate funding. Some people are in favour of heavily taxing inheritance since most elderly people in the UK are well off; others think it is wrong to tax inheritance. Also, people aged 65+ have substantial assets in the form of housing, because of substantial increases in home ownership and house values over the past couple of decades and most Government proposals aim to tap into this wealth to fund care for the current generation of older people – e.g. through a compulsory social insurance scheme to which older people would contribute; voluntary (private) insurance; a 'partnership' scheme in which the Government funds a proportion of care needed and matches the funding contributed by the individual. Other proposals are a National Care Service (like the National Health Service), a social insurance or a voluntary insurance scheme. This issue has been very prominent in the media and is completely unresolved. Government recognises the need for increased funding but is reluctant to increase taxation. A solution is also needed that does not penalise people from saving.

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APPENDIX I: Guidance on eligibility criteria (from Eijlder et al 2009, p. 99-100)

FAIR ACCESS TO CARE SERVICES GUIDANCE ON ELIGIBILITY CRITERIA FOR ADULT SOCIAL CARE:

The eligibility framework is graded into four bands, which describe the seriousness of the risk to independence or other consequences if needs are not addressed. The four bands are as follows:

Critical – when

- life is, or will be, threatened; and/or
- significant health problems have developed or will develop; and/or
- there is, or will be, little or no choice and control over vital aspects of the immediate environment; and/or
- serious abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out vital personal care or domestic routines; and/or
- vital involvement in work, education or learning cannot or will not be sustained; and/or
- vital social support systems and relationships cannot or will not be sustained; and/or
- vital family and other social roles and responsibilities cannot or will not be undertaken.

Substantial - when

- there is, or will be, only partial choice and control over the immediate environment; and/or
- abuse or neglect has occurred or will occur; and/or
- there is, or will be, an inability to carry out the majority of personal care or domestic routines; and/or
- involvement in many aspects of work, education or learning cannot or will not be sustained; and/or
- the majority of social support systems and relationships cannot or will not be sustained; and/or
- the majority of family and other social roles and responsibilities cannot or will not be undertaken.

Moderate - when

- there is, or will be, an inability to carry out several personal care or domestic routines; and/or
- involvement in several aspects of work, education or learning cannot or will not be sustained; and/or
- 100
- several social support systems and relationships cannot or will not be sustained; and/or
- several family and other social roles and responsibilities cannot or will not be undertaken.

Low – when

- there is, or will be, an inability to carry out one or two personal care or domestic routines; and/or
- involvement in one or two aspects of work, education or learning cannot or will not be sustained; and/or
- one or two social support systems and relationships cannot or will not be sustained; and/or
- one or two family and other social roles and responsibilities cannot or will not be undertaken.

7) LONG-TERM CARE IN SWEDEN

* *Country expert: Marta Szebehely*

Current modes of care provision

The policy in Sweden is that anyone who needs help to support him/herself in his/her day-to-day existence has the right to claim assistance if his/her needs can not be met in any other way. However, the annual public budgets, rather than the health and capabilities of the people themselves, decide how many older people are defined as needing help. It is possible to appeal to court against a decision. Generally, health care is targeted on those with a need for more comprehensive care.

There is no legal requirement for relatives to contribute to the care giving, but it is expected that they take up some responsibility for long-term care. It is estimated that in practice, two-thirds of the total volume of long-term care is care by **home intimates (9)**. It is 2/3 of all hours of care provided to elderly living in their ordinary homes that is estimated to be provided by family and friends; care provided in residential care facilities is not included; neither in the numerator nor in the denominator.

Among needy older people living at home, many more receive care by **home intimates (9)** than care by **home nursing (3)** or **nursing (1)**, with the exception of the unmarried *and* childless. Institutional settings, the balance between formal and informal care is more evenly. Home medical care, which seems to be a rather intensive form of **home nursing (3)**, is received by the very old. Of those receiving this kind of care, 70 percent were aged 80 or older. **Home nursing (3)** remains available when care needs become very high. Compared to most other European countries, the percentage of people receiving **home nursing (3)** is relatively high. 8 to 9 percent of people aged 65 and older receive **home nursing (3)**, and another 8 percent that do not receive home care, do make use of services like social transport and meals-on-wheels.

Respite care, which can be regarded as a temporal form of **home nursing (3)** or **nursing (1)**, is available in all municipalities for people needing help with instrumental activities of daily living and for people needing help with personal activities of daily living.

The attendance allowance is a cash payment to the dependent person, which they can use to arrange care by **paid home intimates (7)** if the municipality approves it. Attendance allowance as well as a family member employed as care worker is a decision taken by each of the 290 local municipalities in Sweden. Some municipalities do not accept any paid family care at all. Only 0.1 percent of people over 65 make use of it. Carers can also be employed by the municipality. This often happens with carers of non-western migrants, because organized care providers do not know how to serve these groups. This would be classified as care by **home intimates (7)**.

Note that attendance allowance is not the only form of paid family care: there is also the possibility to be employed as a care worker, caring for a family member (if the municipality accepts it). More important is the Carer allowance (temporary care leave for 'end of life' care) introduced in 1989. This is part of the national social insurance scheme, which gives the family or friend to a person who is fatally ill the right to be with that person (providing care or not) for all together 20 weeks (increase from 12 weeks since

this year) and paid up to 80 percent of lost income. Also the personal assistance scheme may be used to employ a family member or a friend, see below under disability.

Living at home for as long as possible is a right. No-one can be forced to make use of **nursing (1)**. This form of care is regarded as the last alternative. Access to **nursing (1)** is regulated by need. Persons with severe dementia receive the highest priority when it comes to granting admission, and thereafter, those with greater care needs. In assessing eligibility, attention is paid to health, housing situation, and in case of home care, to the availability of a family network (although this not in line with the family legislation). The average age of admission into **nursing (1)** is 83-84. Between the age of 90 and 95, **nursing (1)** replaces **home nursing (3)** as the dominant form of organized help. Compared to most other European countries, the percentage of people making use of **nursing (1)** (estimated at 6 percent of people over 65 years of age) is relatively high in Sweden, but the figures can be skewed by the fact that it integrates all forms of facilities including sheltered housing which is often not included in measures of residential care.

Elderly persons move to a facility if they can no longer cope at home, and if this is assessed by the municipality. This is typically the case if persons are suffering from dementia and live on their own.

Historical developments in long-term care

Traditionally, there has not been an expectation that **(paid) (home) intimates (6, 7 and 9)** bear the primary responsibility for care work. Care by **home intimates (9)** was 'discovered' in the late 1970s/early 1980s. Since then, an increasing amount of care-giving has been care by **home intimates (9)**.

The use of **home nursing (3)** has been waxing and waning over the past decades. Whereas virtually no-one over the age of 65 was supported by **home nursing (3)** in 1950, 16 percent were in 1975. After this point, the percentage decreased to 9 percent in 2004. From the 1980s onwards, assessment criteria have become more restricted and help is postponed until there is greater need. However, the volume of service input per person has substantially increased on average. The Ädel reform of 1992 has reinforced the tendency to target services on the most dependent persons. Statistics confirm this tendency. Compared to the late 1980s, in the early 2000s older persons with care needs concerning IADL (Instrumental Activities of Daily Living) less often receive *only home nursing (3)*, and more often receive *only* care by **home intimates (9)** or a combination of the two. Older people with care needs concerning IADL *and* PADL (Personal Activities of Daily Living) less often receive *only* care by **home intimates (9)**, and more often a combination of care by **home intimates (9)** and **home nursing (3)** (Sundström et al. 2006: 772). Other statistics indicate that the proportion of people aged over 65 that received **home nursing (3)** shrunk from 13.4 percent in 1990, to 8.9 percent in 1995. The percentage remained stable at this level until 2000, when the percentage was 9 percent (OECD 2005: 41, 86). Pavolini and Ranci (2008: 253) refer to statistics indicating that the percentage of elderly receiving **home nursing (3)** was reduced from 13 percent in 1990, to 8.5 percent in 2004. Glenngård et al. (2005: 85) present statistics that show that even among the very old targeting of services has taken place. Whereas in 1993, 23 percent of people aged 80 or older received **home nursing (3)**, this percentage had

dropped to 19 percent by 2003. Statistics also confirm that until quite recently, **home nursing (3)** to the most needy has become more and more comprehensive. The percentage of people receiving home *medical* care in 2005 had risen by 7 percentage points compared to 2000. In almost 70 percent of the cases this kind of care was combined with (the less intensive) home help, which represents an increase of 9 percent compared to 2000 (Aronsson 2007: 240). The emphasis has increasingly shifted towards granting **home nursing (3)** to people with PADL-needs, and away from people with only IADL-needs.

There was a decline in home based care between 1980 and 2000, parallel to a less drastic decline in residential care. Since 2000 there has been a drastic decline of residential care and an almost as clear increase of home based care. Glengård et al. (2005: 85) report that the number of elderly people receiving home-help services increased by about 6 percent between the year 2000 and 2003. However, more in line with the tendency towards targeting services to the most dependent older people is that it was the group of people aged 80 years or over and receiving home-help services that increased, whereas the size of the group comprising people aged 65-79 was reduced. According to Sundström et al. (2006: 780) the changes that have taken place in the 1990s resulted in all groups of clients receiving less home help, except for the unmarried *and* childless. The current trend is still to target public services like **home nursing (3)** based on need and – although implicitly - those without family networks. Another more recent development that is described in the literature, is the expansion of in-home respite care, which can be classified as temporary **home nursing (3)**.

There is a long-standing system of care by **paid home intimates (7)**, in the form of wages from the state or state agencies to support an intimate pre-existing care relationship. This system is in decline. Paid family care (both attendance allowance and employment as family carer) is declining – from around 45 000 the two together around 1980 to 7 000 today. Municipalities are cutting back on benefits for full-time care by **paid home intimates (7)**. The argument is that professional care is regarded as better care, and family care is regarded as a gender trap. The Attendance Allowance – used by only 0.1 percent of people over 65 – which older people can use to pay caregivers if the local authorities approve of it.

In the 1950s, full-time **nursing (1)** was the only option open to older people who could or would not rely on care by **home intimates (9)**. Many people were admitted in an early stage, and made use of around-the clock **nursing (1)** for a long time. It has been estimated that about 15 percent of older people in Sweden used around-the-clock **nursing (1)** in the last part of their life in that era. This percentage was 30-45 percent in the 1990s, which indicates that the proportion of older people making use of this form of care provision increased between the 1950s and the 1990s. The following statistics suggest that nowadays people are admitted to around-the-clock **nursing (1)** in a later stage than in the 1970s: in 1950 about 6 percent of older people received around-the-clock **nursing (1)**, the figure was 16 percent in 1975, and then slowly decreased to 7 percent in 2004. After the Ädel reform in 1992, around-the-clock **nursing (1)** –like **home nursing (3)** – has come to be targeted more closely on the most dependent. Around-the-clock **nursing (1)** has been replaced by **home nursing (3)**. Stricter needs assessments are made before anyone is judged in need of a place in special housing. Since the Ädel reform, elderly have become more frail and dependent both in terms of functional and cognitive capacity

at the point that they move to special housing. A number of statistics regarding people making use of around-the-clock **nursing (1)** are available. However, these statistics do not all neatly match the developments described above. According to OECD (2005: 41) the percentage of people aged 65 and older receiving full-time **nursing (1)** was 6.4 percent in 1991, 8.8 percent in 1995, and 7.9 percent in 2000. Pavolini and Ranci (2008: 253) present statistics indicating that the percentages were 8.4 percent in 1993 and 6.7 percent in 2004. Tjadens et al. (2005: 23) also disagree with the tendency described above. They state that **(home) nursing (1 and 3)** has not been substituted with home care, but with care in smaller facilities. According to them, the elderly do not stay in their own homes longer than before.

When older people receive full-time **nursing (1)**, friends and family are usually frequent visitors. In recent years, care personnel are increasingly focusing on the family and friends to collaborate, thereby adding care by **intimates (6)** to around-the-clock **nursing (1)**.

Concerning the role of **freelance nursing (4)**, we know that elderly with higher incomes to some extent have replaced the reduced home care by buying private services, but whether these services are provided in the formal or informal economy and by migrant or non-migrant workers is not known. (Elderly with lower incomes have turned to family instead).

Care by **paid home intimates (7)** was traditionally very common in Sweden. However, since the 1980s the role of care by paid family at home (7) has declined and the role of care by unpaid family at home has increased.

Long-term care for target groups

Long-term care for people with intellectual disabilities

For adults with intellectual disabilities two types of housing dominate. The first and most dominant type is a group home, consisting of three to five units. Each person in the group home has his/her own unit with bedroom, sitting room, bathroom and kitchen. In addition there tend to be a communal room and a staff room. The second type of home is described as semi-independent housing. This can be units in an apartment block, or several units scattered around a housing project area with one unit serving as staff unit, service center and communal area. The care received by persons living in these types of housing would probably be characterized best as **nursing (1)**. The statement of Glengård et al. (2005: 88) that “approximately 70 percent of those with intellectual disabilities live in their own homes” seems to be somewhat at odds with the above. However, living in their own homes is opposed to living in institutions by Glengård et al. So possibly they consider group living and semi-independent housing as living in one’s own home. 30 percent would, according to Glengård et al., be living in institutions. But this is at odds with another statement by Tossebro (2006: 131), saying that all institutions are closed in Sweden. That is because special housing refers to other forms of semi-institutional settings. There are different forms of housing with services attached to them where some people with learning disabilities live. These may be group homes or apartments with staff in an apartment in the same building. Out of around 50,000 individuals with learning disabilities slightly more than 20,000 live in these forms

of special housing. The housing situation of people with intellectual disabilities in Sweden remains unclear.

One more piece of information available is that most people with intellectual disabilities have day activities in day centres or sheltered workshops. This would be classified as **nursing (1)**. Personal assistance (see below) is an option also for persons with learning disabilities, but it is used only by a couple of thousands.

Those 30,000 persons that do not live in special housing mostly live on their own and receive **home nursing (3)**. They typically have daily activities, which can be school, work or leisure. A few are eligible for Personal Assistance, this PA could be a family member or not. A few also live with their parents. But the typical situation is that persons live on their own, have daily activities (**nursing (1)**), and receive a combination of **home nursing (3)** and care by **home intimates (9)**.

Intellectually disabled: historical developments

In the 1950s and 1960s the service ideal was **nursing (1)** in large institutions. For most people, the only alternative was care by **home intimates (9)**. But already in the 1950s, some forms of semi-independent living and group homes slowly started emerging. However, these forms of accommodation would remain a small part of the service system until the 1970s. Initially, the new types of services were meant to create alternatives to institutions, not to replace them. But gradually, institutions came to be seen as a problem. In 1967, changes were introduced to avoid unneeded institutionalization. The preferred option for children became special classes at local schools; all children were granted the legal right to education, and children who could not live with their families were to be accommodated in small 'pupils homes'. For adults, group homes and supported independent living programs became the preferred options. The institutions came to be seen as a last resort. Adults with severe disability were still expected to live in institutions. In the 1970s, a broad range of options was provided. Part-time **nursing (1)** in the form of day services, non-residential schools and sheltered workshops were provided for people living with their family. When these new services were first emerging, they were targeted at children with mild and moderate intellectual disabilities. But already in the early 1970s, even children with severe and profound intellectual disabilities were provided with alternatives to around-the-clock **nursing (1)**, after being granted the right to education in 1967. According to Tossebro (2006: 125), these changes "took the shape of a new division of labor between the public and the families - from the earlier 'either family or total care' to the current 'both family and public support'." A combination of **nursing (1)** on the one hand, and care by **home intimates (9)** and/or **paid home intimates (7)** on the other hand, became dominant. The number of residents in institutions peaked in 1970-1971, and then started decreasing. In the 1970s, there was a real take-off of alternatives to institutions. In addition to the new forms of housing, day services such as schools and sheltered workshops expanded during the 1960s, 1970s and 1980s. According to Tossebro (2006: 127-8), "the first years of deinstitutionalization in Scandinavia were characterized by four developments: children gradually disappeared from institutions and residential schools; day time options were created for adults and adolescents living with their family; institutions were normalized; and adults with lesser needs were resettled in the community." The number of beds in institutions declined by 15 percent in the 1970s, and the decline accelerated in the 1980s. In the mid-1980s, more

persons with intellectual disabilities were living in the community than in institutions. In 1985, a new law was introduced that decreed that admissions to institutions were no longer permitted unless a crisis existed. In the 1990s Sweden was closing its institutions. In 1997, the Swedish Parliament enacted mandatory closure, and by the deadline in the year 2000, only 80 individuals remained. Currently, all institutions are closed in Sweden.

Long-term care for individuals with physical disabilities

Physically disabled persons are entitled to **(home) nursing (1 and/or 3)** in the form of personal assistance¹, contact persons, and daily activities. Care by the private network, **(paid) (home) intimates (6, 7 and 9)** is not obligatory. Access of physically disabled persons to **(home) nursing (1 and 3)** and care by **paid home intimates (7)** is rationed by annual budgets. In general, the public only pays for around-the-clock care by **paid home intimates (7)** in very remote areas, where no alternative is available. Assessment of dependent people for **nursing (1)** takes into account the health and housing situation of the applicant, and often also their family network. Very few individuals with physical disabilities live in anything close to an institution (group homes or the like). But this is not because of strict targeting, and housing situation or family network is not taken into account.

The majority of persons with disabilities live on their own. Persons with mild disabilities typically receive care **home intimates (9)**, sometimes combined with **home nursing (3)**. The policies that apply to the elderly also apply to persons with physical disabilities. Persons with severe disabilities qualify for Personal Assistance. This is granted if they need more than 20 hours for feeding, dressing and communicating. The Personal Assistance scheme offers persons over 100 hours of care a week on average.

The ambitions of the home care legislation on the one hand, and the Disability Act (of which the Personal Assistance scheme is a result) on the other, differ to the extent that the ambition for the first is to help people manage in their own home, whereas the ambition of the Disability Act is to achieve full participation in society. The Personal Assistance scheme is only available to people who become severely dependent before the age of 65.

Physically disabled: historical developments

The resources for disability care have expanded significantly since the mid 1990's (a totally opposite trend compared to care for elderly people). There are no signs that paid family care for people with disabilities would be more common in remote areas. As mentioned above those who are eligible for the personal assistance scheme may choose to employ a family member and around ¼ of all the assistants are family members (note that this does not imply that ¼ of the users employ family members – usually people have a mix of family and non-family assistants, but the numbers are not known). Until the 1970s the choice was between either care by **home intimates (9)** or **nursing (1)**.

¹ The personal assistance scheme is not restricted only to persons with physical disabilities; it may be used also by people with learning disabilities or psychiatric disorders. It is used by around 15,000 severely disabled persons, average >100 hours/week; ¼ of assistants are family members

Persons with physical disabilities would traditionally be subject to the same regulations as the elderly. This means that for this group as well, **home nursing (3)** has increasingly been targeted to the most serious cases. However, for the most serious cases the generous Personal Assistance scheme has been made available in 1994, which means that they receive much more care than before.

Long-term care for individuals with psychiatric problems

Persons with chronic (more than three months) care needs as a result of problems of psychiatric nature usually receive **(home) nursing (1 and/or 3)**.

Persons with psychiatric problems most often live in their own apartment; receive **home nursing (3)** and have daily activities (**nursing (1)**). A few receive Personal Assistance (if they are assessed as needing at least 20 hours of personal care: feeding, dressing and communication).

Psychiatric patients: historical developments

In 1995, a reform was introduced signifying a change from viewing psychiatric care in terms of cure, to emphasizing the ability to handle daily symptoms in social life. From that moment on, municipalities have had to pay for persons with psychiatric problems receiving around-the-clock **nursing (1)**. Possibly as a result of this measure, there has been a steady decrease in the number of psychiatric hospital beds during the 1990s: from 14 533 in 1990 to 4 606 in 2003. Glenngård et al. (2005: 88) state that Swedish psychiatric care has become more outpatient-oriented over the past 50 years, and that the share of around-the-clock **nursing (1)** in the total amount of psychiatric care has been decreasing.

Critical issues and developments in Swedish long-term care

Vulnerability of care provision

Most people that need care receive care. However, as a result of the decline of **nursing (1)**, some people that are anxious and would like to be admitted to a facility, are instead awarded **home nursing (3)** six times a day. But living alone can make these persons very anxious. Thus they do get help, but not the help that works well for them, due to the absence of short-term **nursing (1)**. This is mainly a problem for the elderly, and is mainly the result of the closure of residential facilities since 2000.

A second issue is that persons with high level care needs do get this help, but often the coordination between different providing organizations is insufficient.

In the 1970s one could choose between living in an institution (resulting in high safety and high dependency) and receiving family care at home (low safety, low dependency). Nowadays people can better pick a balance between the two extremes. However, since the 1990s people have been able to receive less home care, resulting in increased vulnerability. Thus, compared to the 1960s and 1970s, care is more often sufficient because it is possible to opt for a better balance between dependency and safety. But compared to the 1980s, it is less often sufficient.

Re-allocation of responsibilities

The family provides most care and has the *care provision responsibility*. In the last two decades the role of family care has increased. This was an unintentional result of the decline of care provision by the municipalities. Home care provisions have also become provided slightly more by the market since the 1990s: nowadays 15 percent is provided by the market. This is not nursing care, but household care. All other professional care is provided by the municipalities. The increase of the role of the family has been stronger than that of the market.

The *financial responsibility* is more shared. The municipality finances 85 percent of the financial costs for long-term care, the state subsidies 10 percent, and co-payments account for 5 percent of the costs.

The municipality has an important role regarding the *arrangement responsibility*. The municipality typically has to do a needs-assessment after discharge from a hospital. It is the municipality's responsibility to offer care provision. If there are multiple options, the care recipient can choose.

As for the *care support responsibility*, the family carers have the obligation to arrange support. However the actual support is often also provided by voluntary organizations.

Overall, responsibilities are mostly in hands of women, as they perform 70 percent of the care giving, people with low educational levels do more care giving, and non-Western immigrants provide more care (the latter are often employed by the municipalities because the municipalities often do not know what these groups want). None of the groups voice any dissatisfaction about this situation. The decline of home care provision for the elderly has increased the burden for families, which also increases the inequalities above.

Tensions between governments' and citizens' normative expectations

Persons having a voice, or having relatives that can voice claims facilitates access to care giving. This is very much related to class and education. For example, persons with a higher education more often receive Personal Assistance than those with lower education.

There are no policy documents that say that families should do more. Care giving is not regarded as a citizen responsibility by politicians. Elderly prefer to be cared for by professionals, and citizens do not regard it as their task to provide long-term care. There has been debate in the media about the quality of elderly care. According to Szebehely this was the upper middle class elite worrying about their own future, since people that are now receiving care are usually satisfied.

Four years ago there was a short but intense debate before the elections. It was about the lack of residential facilities. The immediate cause was the death of an elderly woman who was anxious in her own home but was not allowed to transfer to a nursing home and then committed suicide. The debate was about whether people should have the opportunity to move to a nursing home if they no longer feel safe in their own home.

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8) LONG-TERM CARE IN NORWAY

** Country expert: Svein Olav Daatland*

Current modes of care provision

Care typically starts in the family, by **home intimates (9)** (partner, parent, children), in particular in a family household. Singles will often go directly to services. Application for services may also come through the General Practitioner and/or the hospital. First level of services is typically **home nursing (3)**, but while specialized help from trained nurses is free of charge, practical help is subject to moderate fees. This can add up to around 2 percent of actual costs for home care and around 15 percent of actual costs of nursing home care) of local government (municipal) services. In larger municipalities, needs are assessed by a care manager (purchaser-provider split), in smaller municipalities needs assessments and service provision are integrated. Persons with considerable needs may be transferred directly from hospital treatment to a facility where they receive **nursing (1)**.

Services are provided according to individual needs and according to the gravity of such needs. Family and financial resources are not relevant for access to care, only needs count, and according to legislation, there is no legal responsibility between adult family generations, except between partners. The legal responsibility rests with the local government (municipality) via the Municipal Health Services Act or the Social Services Act (for persons who are unable to care for themselves). Care by **home intimates (9)** is still considerable, estimated to a 50/50 split between family care and services, the estimated 50/50 split between family and services (more or less informal/formal) include all family on one side and all services (welfare state) on the other, for the most needy, services imply nursing homes, for less needy, services may be practical help or lighter nursing in the home) as far as elders are concerned, and the higher the needs, the more dominant are services. This refers to hands-on-care, while socio-emotional support is mainly a matter for family and other **home intimates (9)**. When personal care is provided in a home setting (3), by a co-residing partner or child, then family care (9) is totally dominant, but of elders with needs for personal care (Activities of Daily Living), the majority receives such care in a care facility as **nursing (1)**, most often a nursing home. **Intimates (6)** then play a supportive role via visiting and taking the patient home for a period and temporary serve as **home intimates (9)**. **Care by paid home intimates (7)** is typically more dominant for younger clients, where cash support are used to support family carers. Cash-for-care arrangements are few in elder care.

This being said, provision of services is in reality also subject to financial and moral considerations. Services are provided within the financial limits of the municipality, while needs for services is seen as needs beyond what the family could/should provide. The translation of “needs” into “rights” is therefore often subject to negotiations.

Historical developments in long-term care

Procedures have been formalized in order to strengthen user rights, so also with legislation and quality standards. More important are changes in the volume and profile

of services. Elder care was traditionally either care by **home intimates (9)** or **nursing (1;** in old age homes). **Home nursing (3)** (practical help, specialized nursing and a number of minor services) developed from the mid 1950s, expanded through the 1970's and leveled off around 1990 and beyond with a small decline the very latest years. Today slightly more than 50 percent of resources are used in home care (including assisted housing) and 50 percent for institutional care (refer to long-term care in general, but an estimated 70 percent of resources to older clients are in institutional care (nursing homes); younger clients are subject to a more community policy regime. 30 years back 2/3 was used for institutional care. The service profile has changed, with a moderate decline in **nursing (1)** balanced against a considerable increase in assisted housing (assisted housing are defined as independent housing, and care here thus as community care, but some assisted housing are close to nursing homes and vice versa, thus blurring the borders between the two), serviced by home care. Younger clients are given priority in **home nursing (3)**, following a deinstitutionalization policy and reforms that transferred the responsibility for these groups (physically and intellectually disabled, psychiatry, drug abuse) to the municipality and so-to speak in competition with elders. Lighter needs, including socio-emotional needs and preventive services, have now less priority. Responsibility for such needs is pushed back on the family, while the most needy is given priority. Because hospitals (a county and state responsibility) have rationalized, and patients discharged (to the municipality and long-term care) much earlier, the local long-term care administrations have hardly been able to cope with the increasing needs, and thus, thresholds for access to services (**nursing and home nursing (1 and 3)**) have been raised.

Norway is still among the top five European countries as far as access to (**home nursing (1 and 4)**) is concerned. Around 42 000 reside in institutions (mainly nursing homes, 90 percent elders). During the Action Plan for eldercare carried out between 1998 and 2005, nursing homes were modernized and more than 20 000 adapted/assisted housing units were built. Today, around 50 000 live in adapted or assisted housing (50 percent elders), of which 20 000 are staffed (i.e. institutions-like). An estimated 15 percent of the 80+ live in homes, where they receive **nursing (1)**, another 10 percent in adapted or assisted housing, receiving **nursing (1)**, in total 25 percent. Close to 40 percent of the 80+ have some home service (3). All in all, around 60 percent of the 80+ have any of these services.

Long-term care for different target groups

Long-term care for the elderly

According to the Social Services Act, providing help to independent elderly in daily living is a responsibility of local authorities and not a family responsibility. Need for care is defined by the person's condition and not by the ability of the family to meet the caring needs. In practice, however, care by **home intimates (9)** is taken into account when sparse resources are to be considered. It is even reported that many family care givers are under pressure due to insufficient professional care. Still on the whole, the care by unpaid family members (9) accounts for somewhat less instrumental and personal care than in other Western European countries. Situations in which elderly people receive care by **home intimates (9)** only, are relatively rare in Norway: of the people aged 75 and over, who live alone, are disabled and received help 9,9 percent received this help from family

only, while in England (26,9 percent), Germany (30 percent) and Spain (39,5 percent) these percentages were much higher (Daatland & Herlofson in Ingebretsen & Eriksen 2004: 34).

Help provided by the public is in most cases initially organized as **home nursing (3)**. That this form of care provision is made available in a relatively early stage compared to other European countries is indicated by statistics that have been reported by Daatland and Herlofson (in Ingebretsen & Eriksen 2004: 35). They report that in Norway one in three of elderly 75+ received formal home help services, compared to one in fifteen in Germany and Spain. In a relatively small number of cases, care by **paid home intimates (7)** is employed, instead of organized **home nursing (3)**. This option is more frequently used in sparsely populated areas than in urban areas. This Care Wage is not means-tested, but is restricted to people having extraordinarily heavy care duties.

Dependent persons have the legal right to live in their own home. The municipality has to supply enough **home nursing (3)** to make this possible. However, if one does choose to make use of **nursing (1)**, the only criterion for admission is degree of dependency. "Considerable needs in connection with personal care" (Ingebretsen & Eriksen 2004: 47) qualify for residential care. When a dependent person receives **nursing (1)**, it is up to the family to decide how much care in a facility as **intimates (6)** they want to provide.

Some care by **volunteers (5)** and some care by **home volunteers (8)** is organized through volunteer centers. But these modes of care provision only account for a small part of care provision in Norway.

Elderly care: historical developments

The number of persons receiving around-the-clock **nursing (1)** because they are living in a residential or nursing home has been reduced since the 1980s. The percentage of people aged over 65 who were living in these environments has been stable between 1994 and 2000, at about 6 percent. The percentage of people aged 67 and over that was living in sheltered housing, which we also consider **nursing (1)**, has increased from 3.3 percent in 1994, to 5.2 percent in 2000.

The proportion of the population aged 16-74 giving care as **(paid) home intimates (7 and 9)** has been somewhat reduced from 1990 to 2000. This could be (but does not have to be) an indication that elderly people have been receiving care by **(paid) home intimates (7 and 9)** up to a later stage.

Long-term care for people with intellectual disabilities

In the 1970s, the service ideal was large institutions. The only alternative to this form of **nursing (1)**, was care by **home intimates (9)**. From the 1970s, alternatives to the secluded life in large institutions have increasingly been provided. This has resulted in the disappearance of these large institutions and the substitution of **nursing (1)** for **home nursing (3)** and **paid (7)** as well as unpaid care by **home intimates (9)**.

Following a deinstitutionalization policy during the 1990s, responsibilities for this group was decentralized (from the county) to the municipal level, and integrated with long-term care for elders and other groups in need. The old central institutions were discharged (1), and replaced by adapted and assisted housing (1) in integrated and normalized environments, while clients should be offered employment in ordinary or

adapted businesses. Normalization is a key word here, and although the reform met considerable debate and conflict, the majority seems now to be in support for the reform.

Long-term care for people with physical disabilities

These needs and persons are integrated in the local long-term care services, but the characteristics of services for this group are responding to the strong ideology in organizations for disabled persons, where disability is seen as much a result of unfriendly environments as of individual functional limitations. Disabled persons should be acknowledged full citizen's rights via compensatory equipment and arrangements. Thus technical aids are important here, as well as adapted/assisted housing, and adapted work and environments more generally. Younger disabled have also access to a Personal Assistant arrangements, or rather **home nursing (3)**, but administered by the disabled him- or herself as the employer), now covering between 2 000 and 3 000 persons. Most disabled children live with their parents, who have access to respite care (1), technical aids, and financial supports of various kinds. As for financial support to family carers, this is mainly intended to compensate parents of disabled children for extra expenses due to disabilities, and in some cases also as payment for the job (care salary). Cash-for-care is still not very common in Norway, and less so than in many other (even Scandinavian) countries. Judged by the media, needs are far from met in these areas.

Long-term care for people with psychiatric problems

Adapted and assisted housing (1) is important also here, as well as occupational activities, preferably integrated into the ordinary work life. This is an area where NGOs have traditionally played a considerable role, and still do, contracted and financed by public money, and under public supervision. Judged by the media, these needs are far from met.

Action plan for mental health and drug problems have been carried out the last decade, and responsibilities for these needs and groups also are transferred to local governments and integrated into the general long-term care system, and supported by specialized personnel.

Critical issues and developments in Norwegian long-term care

Vulnerability of care provision

As home based services to elders are typically very moderate, a few hours a week, and/or a short visit morning and evening by a home nurse, elders with more extensive disabilities need family care and/or care in a residential setting, be it in a nursing home or some form of assisted housing. Only few of these resources are reserved for short-term stays, implying that when new needs arise, nearly all seats are taken already. More short-term accommodations would increase flexibility and flow through the system. Earlier discharges from hospitals add to this problem of poor flow. A new plan of integration between services and levels of government are now launched in order to provide a more integrated chain of services. In short, most service arrangements have difficulty in adapting swiftly to changing needs. More extensive use of short-term accommodations (respite, rehabilitation etc) would also be supportive to family care. Family care may also come in conflict with work, now met by a right to unpaid leave from work when family members need care. But as these leaves are not paid, in reality access is unequal.

Access to services have increased during most of this period, following by a moderate decline in volume of institutional care and home services the last decade or so. Service standards have increased throughout these years, as measured by access to single rooms in nursing homes (95 percent) and nursing homes staffing (1:1). As thresholds for access have now been raised, a growing number with more moderate needs are left without services, while the comparatively fewer with services, receive more generous services than earlier. Compared to most other countries, access to services is generous, but less than the demand, and popular opinion is quite critical to Norwegian elder care, in particular complaining about too few nursing homes.

Levels of services should also be judged relative to the low rates of family households. The great majority of elders are either living singly, or in a two-person household (with partner). The norm of independence between generations is strong. Most elders state a preference of services over family care, and both elders and adult children seem reluctant to expect family care. Services are heavily subsidised, hence personal finances are not limiting access to services. The price for nursing home stay is limited to around 75 percent of an ordinary pension, amounting to around 15 percent of the gross expenditure. Payments for home care are also limited, and constitute around 5-10 percent of gross expenditure for these services.

Re-allocation of responsibilities

Concerning the *care provision responsibility* we see a clear shift. As thresholds for access to services have become somewhat higher (see above), lighter needs go unmet and/or are provided informally by family, friends (or oneself). The more selective provision of services tends to protect the neediest. Local governments have increasingly opened for competition among service providers, and approximately 10-15 percent of service provisions are now contracted out to private organisations or companies, in order to stimulate competition and allow more consumer choice. Most service provision is still public. Only few private-for-profit service arrangement have been established, and then most often in the larger cities.

Concerning the *financial responsibility*, user fees have been small or moderate throughout these years (see above). The financial responsibility for services rests with the central and local government. Adult family members (beyond the partner) have no responsibility. When services are contracted out from the local government to private companies/organisations, they are paid and organised by public money.

The *arrangement responsibility* is a public responsibility. Legislation, financing, and monitoring is a public responsibility, carried out by local governments (municipalities).

As for the *care support responsibility*, priority is and has been given to service provision, while cash and other support for informal carers have been given low priority. Care and attendance allowances are available, even a so-called care wage when burdens are high, but these supports are few compared to resources put into service provision. The later years have shown a growing interest in support to family (and other informal) carers in response to the ageing of the population. Other supportive arrangements are the right to unpaid leave from work, information programs and supportive group for dementia family carers and similar. Financial support is provided by the public, the other supportive arrangements are often carried out via NGOs and volunteers.

In particular, elder care in the family – and even more so in the public services – is mainly a women’s responsibility. Thus daughters, and wives, have a disproportionately large responsibility. Partner care is more equally divided between the sexes, and the least gender equality is found in the professionalised services, where nearly all (90 percent) are women. These inequalities are increasingly recognized, but are so far not addressed effectively in policies. Gender inequalities are not addressed effectively in policies beyond lip service support for higher pay, better education, and more recognition for this work.

Tensions between governments’ and citizens’ normative expectations

Class does not impact access, only indirectly so in the sense that the better off have better housing, economy and social resource to handle dayly life. A few of them may also buy their way into private adapted and assisted housing arrangements. Migrants are assumed to be hesitant to use public services, and/or to be poorly informed about them, but recent impressions are that these attitudes change, and migrants tend to converge towards Norwegian attitudes, although there are still differences. Cash allowances (for family care) are in particular popular among migrants, giving them access to public resources and allowing a traditional family life. Some older migrants are reported to be reserved towards such arrangements. We still know too little about this. More generally, single elders (in part single men) are sometimes given priority over couples, and elders with no family over those with family nearby. Lower level needs, and socio-emotional needs, tend to be given lower priority, and therefore – by omission – left to families. The stronger selectivity vis-a-vis such needs the later years imply some degree of de-familisation of care.

The major controversy in Norwegian long-term care is over nursing homes versus other forms of care. General attitudes are in favour of nursing homes, many local governments, and professionals, favour assisted housing and community care. Also controversial is the public-private debate, and the debate over more private provision of care. All in all, debates tend to circle around the same issues, and be triggered by media coverage over elders in need, being abandoned by municipalities and families alike. The general public is quite disappointed with Norwegian elder care, despite the Norwegian volume being among the highest. And yet, expectations are even higher.

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Part III.

Topics for conference day 1

How does the picture look when we compare the situations and developments in various European countries, as described in the country reports? Using our frameworks of care arrangements and of long-term care responsibilities, what (past and current) tendencies can be found within the organization of European long-term care? Which consequences have these developments for the *vulnerability* of care provision to dependent persons, and for the *inequalities* between citizens? Which of our hypotheses are corroborated?

I. In/formalization and vulnerability of long-term care provision

Similarities:

A first important similarity is the rather negative evaluation of *institutional* care we came across in almost all country reports. In many *home nursing* is developing, either from scratch, like in Greece, or to compensate for de-institutionalization, like in the Nordic countries, UK, and the Netherlands. In Italy home nursing has a special form since it is not provided by a professional organization but mostly by migrant women living with the person whom they care for ('freelance home nursing').

The second important observation is related to the importance of *informal* care: in all countries informal care is – at least in quantitative terms- far more important than formal care, even in the Nordic welfare states. This is in line with the political and popular appreciation of informal care. The character of informal care is changing though, since there is an increase in cash payments in almost all countries, not only to pay for professionals but for non-professionals (volunteers, intimates) as well.

These similarities therefore corroborate our main thesis that the clear boundaries between what used to be categorized as formal and informal care have become increasingly blurred.

Apart from these similarities, many *differences* came to the fore:

The role of the state still varies enormously among European countries, from governments that have to fulfill the legal obligation to provide high-quality LTC to their inhabitants, to states that do not really care, but expect citizens to care for each other. This implies that in some countries legal and/or informal obligations exist to care for others, whereas in other countries there are no such obligations at all.

Next to these differences in the relation between state and citizens, surprising differences occur (and persist) between European countries in the role citizens (have to) play for each other. Whereas everywhere intimates care for each other (though in varying degrees), the presence of volunteers (at home or in institutions) varies dramatically.

As discussed in the Introduction, four types of distinctions are often made between **formal** and **informal** care, depending on whether the focus is the *labour market*, *relationships*, *payment* or *location* involved. We here first ask ourselves what does this mean for our two competing hypothesis dealing with the vulnerability of the care arrangement regarding the aspects of **(1) the labor market** and the **(2) type of relationship?**

1. *Professional care giving is less vulnerable than non-professional care giving, on the condition that there are sufficient public finances available, there is no labor shortage in LTC, and professionals are well-trained and qualified. Non-professional care-giving is valuable, but more vulnerable at the same time, in terms both of its instability (who replaces the caregiver if necessary?) and its potential lack of quality (who guarantees sufficient quality?).*
2. *Professional care giving is more vulnerable because these conditions are seldom met, and are moreover highly threatened with welfare state reform that is taking place today in countries with the most developed welfare states. Family members, partners and close friends are much more reliable over the course of people's lifetimes than the turbulent welfare*

arrangements with unpredictable regime changes, budget cuts and labor shortages.

When we have a look at the country reports, there seems to be some evidence that speaks in favor of hypothesis (1). In many countries informal care giving seems to be at its maximum. Moreover, in some countries the number of (unpaid) volunteers is really limited. Finally, the time intimates can spend on LTC seems to be decreasing as well, since women everywhere enter the labor market and take up demanding jobs (whereas they are used to take on the lion's share of care responsibilities and tasks).

However, we did find evidence for the opposite (hypothesis 2) as well: informal care giving is less vulnerable than professional care giving. This is true for both negative and positive reasons. The negative evidence shows that professional care is vulnerable due to underfunding and limited access (professional care only for the most urgent care needs and not for more moderate ones). But is not just for negative reasons that informal care seems to be less vulnerable: one's intimates are in the end more reliable than professional care givers. Family members, partners and close friends are much more reliable over the course of people's lifetimes than the turbulent welfare arrangements with unpredictable regime changes, budget cuts and labor shortages.

As discussed in the Introduction to the country reports, the third aspect concerns the issue of *payment*, and with that the distinction between *paid* and *unpaid* care-giving. We formulated to competing hypotheses:

- 1. Overall, paid professional care-giving can be expected to be the least vulnerable provision compared to paid non-professional forms of care-giving, let alone unpaid non-professional care giving, the payment guaranteeing more stability and, in some circumstances, more quality as well), or*
- 2. Overall, unpaid care can be argued to be least vulnerable, the payment being too vulnerable to regime changes, budget limits and budget cuts*

The country reports show some support for the first hypothesis, though the financial situation in many countries makes paid professional care-giving more vulnerable than in earlier days. At least as important is that persons who pay and those who are paid for have dramatically changed. In almost all countries, cash-for-care has developed, putting clients and patients in a situation of (relative) power and choice. It has opened up the possibilities for payment of volunteers and close relatives (though not in all countries, e.g. in England the money can not be spent on a family member living in the same house!). Some countries seem to combine the best of the two worlds described in the competing hypotheses: paid home intimates give more stability while at the same time the qualities of care by families and friends remain.

The fourth distinction concerns the **location**: the distinction between *care at home* and *care in a care facility*. The criterion here is whether care is provided in a physical environment to which the dependent person has been moved for the purpose of receiving care from professional care-givers. Two hypotheses are often put forward:

1. Overall, care provided in a facility decreases the vulnerability of care giving because of the constant proximity of professional care givers (so both in terms of stability as quality). When living in an institution, they are subject to procedures that guarantee a minimum of supervision and control, while at home neglect or abuse may happen and go unnoticed.
2. Overall, care provided in a facility increases the vulnerability of care giving because people generally feel more at home in their own homes than in a more impersonal institution. Moreover, when living at their own homes, they are treated with more respect than when they are institutionalized, in which case they run a much higher risk of being reduced to a 'case' or a number.

In those countries where de-institutionalization has developed most, some inhabitants voice worries regarding the lack of care provided in facilities. The reports on Norway and Sweden show for instance that the radical closure of institutions has caused some problems. In Norway some people are in favor of (re-establishing) nursing homes. On the

other hand, we have find support for hypothesis (2), particularly in situations of financial constraints. Care provided in facilities doesn't necessarily provide stability and quality. The country reports show that the difference between facilities on the one hand and home care at the other is perhaps not that big anymore. In facilities, more and more is expected from non-professionals (the help of volunteers and family is needed) and, vice versa, professional help is more and more provided at home. Home nursing (professional care at home) has enormously increased, and in various ways: by regular professionals visiting homes, migrant care workers living at the patients' home, etc.

II. Shifting responsibilities and the effects on inequalities

We will now turn to the second cluster of changes discussed in the Introduction. This concerns the shifting responsibilities within long-term care systems, and the potential effects that these shifts have on inequalities among citizens. *We overall expect that transforming public responsibilities into private responsibilities increases inequalities among citizens, simply because some citizens have more skills and more social and economic resources to take care of themselves and their close-ones than others. And vice versa, shifting private responsibilities into public responsibilities is likely to have the opposite effect.*

When we look at the country profiles, the question whether responsibilities are primarily privately or publicly organized turns out to be of somewhat less importance for causing inequalities than we anticipated. We perhaps overestimated the process of marketization. Though it is obviously developing in various countries, nowhere market relations have become totally predominant. In most countries we researched, it is still a rather marginal phenomenon. Moreover, as some countries show, the implication that the rich pay more for (selective) services, this does not necessarily go hand in glove with a decline in public services.

Inequalities for sure exist, or better: persist. However, the all pervasive divide is the gender divide: in all countries, for all kinds of care (paid and unpaid, professional and

non-professional, institutional and home, organized or independent care) women take on the lion's share. With one (growing) exception: across countries, older men take more and more responsibility for care tasks (except for Italy where unpaid female care work is replaced by paid female migrant workers, and Greece where women still take on 80% of the care at home).

III. Popular experiences and expectations regarding long-term care

Let us now have a look at the third issue of this study. Here we look at the views, the experiences and expectations, of European populations. The issues of vulnerabilities and inequalities are important, but we do not know when these are *experienced* as such by the general public. How do they feel about the contemporary organization of long-term care? And how do they feel about the developments that are currently taking place? If the normative expectations of governments and citizens diverge, this represents a potential threat to the *quality* and *stability* of long-term care provision.

We found quite some gaps between expectations by governments at the one hand, and citizens on the other. Partly as a consequence, in almost all countries volunteers and intimates run the risk of being or getting overburdened. This does not necessarily imply, however, that expectations between citizens and policy totally diverge. As it turns out, in most countries governments take into account 'care cultures' as they have developed over time. Governments and citizens often agree about what might be expected from them – a result of a long history in which care cultures have been formed in close interaction between formal institutions and informal practices. This partly explains why it is so difficult for policymakers to change LTC provisions – and if they do so, why people protest. The recent changes that took place in many countries may be necessary for financial reasons, but citizens often disagree, since these changes are not always in accordance with their experiences, let alone their expectations.

Part IV.

The embrace of responsibility: citizenship and the governance of long term care in the Dutch Social Support Act (WMO)

Evelien Tonkens, Loes Verplanke, Jan Willem Duyvendak and Thomas Kampen

‘Active citizenship’ has become a silver bullet for many Dutch policy-makers. Ministries ranging from education, health, justice and integration to the Home office have policies promoting active citizenship, while local governments, civil society and public service organisations rely heavily on the concept as well. Active citizenship has become a panacea for all sorts of difficulties arising from globalisation, the atomisation of society and democratisation (Duyvendak *et al.* 2010). In the area of health and long term care, the 2007 Social Support Act (WMO in Dutch) is no exception.

The central aim of the WMO is to promote citizens’ participation in society. It emphasises a communitarian form of citizenship – of family members, local communities and civic organisations taking over responsibility for long term care. This communitarianism is surprising since the Dutch patients’ movement since the late 1960s has been quite successful in promoting more republican and liberal notions of citizenship, stressing ‘voice’ and ‘choice’ respectively. How can we understand this late victory of communitarian notions of citizenship? What has happened to voice and choice? This article examines this communitarian victory by tracing the fate of responsibility, choice and voice within long term care since the late 1960s. It draws on the findings of two empirical research projects to see how these broader changes have affected community care for people with psychiatric or intellectual disabilities as well as patterns of care among Dutch citizens more generally.

Late 1960s and 1970s: voice and autonomy as rights

Our reconstruction of the ideal of active citizenship within long term care begins with the 1968 introduction of legislation on health and long term care, the AWBZ (*Algemene Wet Bijzondere Ziektekosten* or General Law on Special Care Costs). The AWBZ was in many ways the forerunner of the WMO. It entrenched legal rights to long term care services, covering long-term social (then often still residential) care for all Dutch citizens. As the AWBZ was a collective fund, all citizens were automatically insured – an extension of the Health Fund Law (*Ziekenfondswet*) of 1941 which guaranteed medical services to those with lower incomes. While the AWBZ did not include welfare services such as the support of social workers, these were heavily subsidised from the 1950s. The legal framework of the AWBZ was the main framework for long term care (by which we mean the broad range of care and support services for vulnerable groups such as the elderly and the handicapped). It protected patients as legally entitled recipients of services – a position that would subsequently be criticised as passive.

The 1970s are well-known for the democratisation of society, in the Netherlands as well as in many other Western welfare states. The spirit of democratisation also infused health and long term care, with many patients’ organisations set up in this period (Oudenampsen 1999). There was little need for patients’ organisations to demand access to services as such, as this was already well established in the two laws that together guaranteed healthcare for all Dutch citizens: the Health Fund Law and the AWBZ. While the Health Fund Law covered the whole range of ‘cure’ services (mainly provided by hospitals and general practitioners), the AWBZ covered long term care services where cure was generally not expected.

Figure 1. The changing legal framework for long term care in the Netherlands

	1940s	1950-2000	2000s
cure	Health Fund Law, 1941: entitlement to cure for low income citizens (those with higher incomes had private insurance)		Health Insurance Law, 2005: universal entitlement to cure for all Dutch citizens
(long-term) care	Denominational non-profit organisations	AWBZ, 1968: universal entitlement	AWBZ continued but restricted; WMO,

		to care	2007: combines parts of AWBZ and Welfare Law; no individual entitlement to services
support (welfare)	charity, subsidised by government	Welfare Law (Welzijnswet), 1994: devolution of welfare services to local governments; no individual entitlement to services	WMO, 2007 (see above)

The Dutch patients' movement channelled much of its energy towards championing liberal and republican notions of citizenship – autonomy and voice, respectively. For patients to gain autonomy, it was deemed necessary to free them from paternalistic and authoritarian professionals (Duyvendak 1999; Tonkens 1999). In practice, professionals and informal care-givers played important roles in promoting the ideal of patient autonomy. Professionals criticized *themselves* and their colleagues for being paternalistic and authoritarian. For example, in the critical democratic movement in psychiatry – the so-called anti-psychiatry – psychiatrists themselves played a leading role (Blok 2004). More generally, the anti-authoritarian mood was strong in the Netherlands as it was supported and often instigated by the political elite itself. It was not only psychiatrists who criticised their own practice; members of the elite in politics, education, healthcare and other fields surpassed each other in self-criticism (Hutschemaekers and Oosterhuis 2004).

Thus the democratisation of health and long term care targeted professionals from the outset. The main enemies of the patients' movement were healthcare professionals and their organisations, and to an extent (informal) care-givers accused of blocking patients' freedom and autonomy (Tonkens 1999). The government was not the main target – mainly because it collected and distributed most of the funds but did not control health and long term care, which were organised and managed by denominational non-profit organisations. This situation of indirect government power continues today, though the WMO does give more responsibility to local governments.

In addition to demands for greater autonomy, patients' organisations also began to lobby for influence in health policy-making, aiming to institutionalise the voice of

patients in healthcare practice (Oudenampsen 1999; Duyvendak and Nederland 2007). The government readily acknowledged patients' rights to participate in decision-making in 1974, though initially this had little practical effect.

1980s: voice from right to duty

Participation in decision-making was again emphasised in the national government's first white paper on patient policy in 1981. Over the ensuing years, patients' organisations were admitted as members of regional and national decision-making boards as policy-making could hardly be considered legitimate without patients' voices. Patients' organisations were granted subsidies to improve the quality of their work, and were backed by laws enforcing their voice in policy-making and within health and long term care organisations (Oudenampsen 1999; Trappenburg 2008).

Why were patients' organisations' demands for voice so successful? One reason was the spirit of democratisation. It was felt that patients should be empowered to fight the necessary battle against paternalistic and authoritarian professionals. Another reason was the government's interest in delegating power. The Dutch government only had indirect influence in this area as health and long term care were mostly provided by collectively financed but privately-run denominational organisations. With the rapid expansion of the welfare state between 1950 and 1980, the government gained influence and responsibilities, particularly for the regional spread of services; nevertheless, its powers remained limited. Meanwhile, costs kept rising. Around 1980 the dominant view was that the welfare state had expanded beyond its limits. But how were rising costs to be contained? As the central government struggled to meet its obligations and its limited power to reduce costs, it had an interest in sharing the burden. Patients were good candidates for this, not because they were expected to reduce costs but because they were needed to share responsibility for policy-making.

The idea that the government should withdraw gained ground among policy-makers in the 1980s, not only in healthcare but in many other fields. It was embraced by thinkers from across the political spectrum, a response to what was then considered the

crisis of the welfare state. While one would expect government withdrawal to be embraced by conservative thinkers and policy-makers, it was also supported by left-wing intellectuals. The welfare state, the latter argued, had granted liberal rights to services, but this had also created passive, calculating citizens. The idea was that if the government withdrew and delegated responsibility back to citizens, they would become more active and responsible.

Dutch intellectuals, in the spirit of critics such as Ivan Illich and Jacques Donzelot, thus criticised welfare policies for their disempowering and medicalising effects (Tonkens and Weijers 1999). While the welfare state had promised to empower citizens and provide them with the necessary conditions for actively participating in society, it had instead made them passive, lazy, calculating and dependent. These intellectuals thus supported the idea of government withdrawal, which would more or less force citizens to regain responsibility for their own lives.

But to whom should government delegate its responsibilities? Not to professionals and their organisations, so successfully attacked in the 1970s as paternalistic big spenders (Tonkens and Duyvendak 2003; Kremer and Tonkens 2006). A decade later the logical answer would have been ‘the market’ but this made little sense in the early 1980s when there was hardly a market to be found and corporate actors were more associated with exploitive capitalism than with containing costs. Who was left? Patients! Who else could be made jointly responsible for painful measures to reduce costs? The idea initially appeared in the central government’s first white paper on patients’ organisations, *Patient Policy* (Ministerie van Volksgezondheid en Milieuhygiëne 1981), which gave greater credence to patients’ voices. *Patient Policy*, however, did not frame this exclusively as a right, as patients’ organisations had advocated. There was also a sense of duty – of patients having to shoulder greater responsibilities in the face of government retreat.

Alongside democratic motives, then, the government supported patients’ demands for voice as this fit its aim to make patients and citizens more responsible in the management of healthcare and to reduce costs. The government thus turned to subsidising patients’ organisations to promote patients’ rights and responsibilities. For their part, patients’ organisations welcomed the subsidies and their new-found voice as they saw these as extensions of their rights rather than of their duties.

The concept of citizenship had thus entered the discourse by the end of the 1980s. It could be embraced by both the government and patients' organisations as it contained both rights and duties. The government charged its main advisory board – the Scientific Council for Policy-Making (*Wetenschappelijke Raad voor het Regeringsbeleid* or WRR) – to produce a report on 'contemporary citizenship', which appeared in 1992. While the report pushed the notion of citizenship higher up on the political agenda, its pleas for pluralism and neo-republicanism (academically rephrased in Van Gunsteren 1998) had little effect.

The patients' movement now also began to frame its demands in terms of full citizenship – of all citizens having equal rights to participate in society regardless of their illnesses or handicaps. All people should be able to live independent lives, move freely, make their own choices and be treated with respect. Articulate individuals with physical handicaps were prominent among those who embraced this notion of citizenship. They welcomed it as a possibility to distance themselves from stigma and to stress that, despite illness or handicap, they were citizens like anybody else (Duyvendak and Nederland 2004).

1990s: choice and autonomy from rights to duties

During the 1980s, republican demands for democratic participation emanating from the patients' movement were embraced by a coalition government of Christian Democrats and free-market Liberals seeking to encourage citizen responsibility and to contain public expenditures. During the 1990s, similar developments occurred with the rights to choice and autonomy. While the republican duty to participate in politics continued to be emphasised, it was now joined by duties to choose and to be autonomous. Again, what were first claimed as rights (to autonomy and choice) were now reframed as duties.

In line with what happened in many other Western welfare states, the 1990s saw the rise of neo-liberalism and the introduction of market language and mechanisms in the public sector. The Dutch government's 1981 white paper *Patient Policy* had already pointed to the role of patients as consumers. Patients were also entitled, it argued, to

participate in decision-making. This was institutionalised in regional planning as well as in care organisations, which were obliged to install clients' boards from 1996.

As the marketisation of health and long term care proceeded in the 1990s, increasing emphasis fell on the role of the patient as consumer. This was welcomed by the patients' movement as it fit its aims of greater independence and autonomy. The market moreover allowed exit from patronising professionals as patients could exercise their freedom of choice by exchanging one service provider for another. With the rise of quasi-markets and market-oriented language in the 1990s, the patients' movement embraced the idea of citizen-patients 'steering' social services by choosing between competing services.

The Dutch patients' movement invested great effort in positioning itself as a movement of consumers. As consumers responsible for their own choices, patients were entitled to be well informed (Trappenburg 2008; Oudenampsen 1999). The patients' movement demanded individual rights to better services, more individual consumer choice, and more control over what was offered. Personal budgets (*persoonsgebonden budgets* or PGBs) were introduced in the 1990s to strengthen the patient's role as a consumer.

The dual roles of patient and consumer became the pillars of patients' organisations in the Netherlands. Regional and national umbrella organisations are known as the Dutch Patients and Consumers Federation (*Nederlandse Patiënten Consumenten Federatie* or NPCF), though from the 1990s 'patient' was generally replaced by 'client' or 'consumer' to get rid of associations of passivity and to underline independence and choice.

Personal budgets were attractive for policy-makers as well. Personal budgets reduced their responsibility to arrange for services and got rid of the hated waiting lists. Policy-makers could simply delegate problems to patients in the name of autonomy and choice. Autonomy and choice were such dominant ideals that no one criticised the PGBs. From their introduction in the early 1990s, they experienced explosive growth (Kremer 2006).

The government embraced autonomy and choice for patients. This could be seen in its 'Choices in Care' project, which began in 1988 and invited citizens to discuss

cutbacks in the face of rising costs. Discussions were organised across the country. If we need to make hard choices, the government asked all kinds of citizen groups, which options do you prefer?

With the rise of marketisation in the 1990s, ‘choice’ and ‘demand steering’ emerged as key terms. Consumers choosing between insurance companies and healthcare providers were to underpin the marketised system. While efforts towards the full marketisation of healthcare failed in the 1990s, the language and ideas remained. The plan was reintroduced at the end of the century, this time successfully, and eventually resulted in a new healthcare insurance law.

The concept of autonomy was likewise reframed as a duty during the 1990s, particularly for many psychiatric patients and people with intellectual disabilities. They were urged and sometimes even forced to leave residential institutions and to live independently in shared regular housing, or on their own in regular neighbourhoods (Verplanke and Duyvendak 2010).

Because the government wanted active patients to assume responsibility – and because the patients’ movement, well-adapted to the new consumerist discourse, was an attractive policy-making partner – patients’ organisations were generously subsidised and given room to voice their opinions. All health regions now gained Regional Patients/Consumer Platforms (RP/CPs), consisting of representatives of patients’ organisations. Alongside regional and local government bodies and health insurance companies, RP/CPs helped to write the regional white papers (*regiovisies*) that set out the main lines of policy.

Organisations of professionals were generally not part of such deliberative procedures. They were still weakened by earlier attacks on their paternalism and authoritarianism and considered too self-interested to be partners in deliberation. Subsidies to professional organisations were thus not increased in the same manner as for patients’ organisations, and in 2002 the Ministry of Health cut their budgets – ironically just before the public debate on the reappraisal of professionals got underway (Tonkens 2010). With the introduction of the WMO, the organisation of municipalities (VNG) arranged a transitional period so that the cutbacks would only be felt a few years hence (see Pierson 1996, 2002).

After 2000: community participation from right to duty

What has been the fate of voice, choice and responsible participation under the WMO? We first examine the ideal of choice by patient-consumers, so cherished by the patients' movement of the 1990s. The WMO restricts choice to the new practice of tendering for services, particularly for home cleaning for the elderly and the chronically ill, as well as for welfare services. Care organisations competing for contracts from local governments, it was argued, would result in lower prices and greater consumer choice. While tendering for contracts did result in lower prices, this was achieved by hiring lesser qualified personnel and reducing the quality of services. The choice, moreover, was for local governments and not for citizens.

What explains this absence of choice for citizens under the WMO? Why did the legislation pass without major protest? Partly this was because choice was concentrated in the area of healthcare (for 'cure' and personal budgets). But it also emerged that citizens were less enthusiastic about the rights and duties of choice than policy-makers and patients' organisations had hoped. In the area of health, virtually everyone valued solidarity and equality over freedom of choice (SCP 2003; Burkestichting 2004).

Choice was less valued than expected in other areas as well. For social security, 75% of citizens stated that they did not want to choose their own pension providers, preferring the current obligatory system instead. Particularly those with higher educations disliked the new choices as they were too time-consuming (SCP 2003; Burkestichting 2004). Even the association for people with personal budgets, Per Saldo – which had always fought for freedom of choice – tempered its enthusiasm. Per Saldo now maintains that managing personal budgets is a complex matter not suitable for everybody; people have often been given this responsibility without ascertaining their ability to handle it (Per Saldo website).

But choice is not only a right, argued the Dutch Minister of Health Ab Klink in 2008; it is also a responsibility. Consumers of healthcare must choose carefully. They cannot simply assume that every service provider will guarantee quality care: 'Those who

simply presume that it [the quality of health care] is OK can get into serious trouble', he was quoted as saying (*Trouw*, 28 October 2008).

Citizens find choice much less attractive when it becomes a duty. Here it makes sense to distinguish between *steering* and *empowering* choices. Steering choices are those that citizens are required to make in order to play their part in governing (marketised) social services. Empowering choices are those demanded by citizens themselves to raise their quality of life (Tonkens and Swierstra 2005). To limit the burden of choice as a duty, it needs to be accompanied by a quality default option for those who do not want to choose or are unable to do so.

While the ideal of choice takes a backseat in the WMO, the ideal of autonomy does not. Empirical research on networks of care-givers around patients has found that the WMO requires a great deal of autonomy and self-management: citizens who arrange their own lives and help from family members, neighbours, voluntary organisations, and when necessary, from professionals (Tonkens *et al.* 2009). Less capable individuals, however, can easily fall through the cracks. Many deinstitutionalised psychiatric patients and people with intellectual disabilities ended up isolated in their new neighbourhoods as they lacked the competencies to actively manage their own relations (Verplanke and Duyvendak 2010).

Finally, the ideal of democratic participation is present in the WMO, albeit not as a core concern. It can be seen in the legal obligation of local governments to give citizens a say in policy-making, though legislation does not clarify how this should be done. This forces local governments to reflect on the matter. Often they end up combining existing advisory boards for the elderly and the handicapped. In this way the obligation is fulfilled and local governments can concentrate on other, more demanding obligations.

Rediscovering civil society

How does the ideal of responsible participation figure in the WMO? The drive towards government withdrawal regained prominence in the new millennium, this time with a communitarian twist. Civil society was rediscovered as crucial for creating long term

care, well-being and social cohesion. The rediscovery of civil society was partly a response to the criticism that society had become overly atomised. Surveys repeatedly found Dutch citizens to be longing for ‘community’ and social cohesion, complaining about the selfishness and egocentrism of others; surveys also found that many citizens were happy with their own lives but unhappy about society as a whole. As in many other comparable countries, there was a rising desire for community (Bauman 2001; Koenis 1997) that bureaucrats could not address without the help of civil society.

Inspired by the American communitarian Amitai Etzioni, many now hoped that civil society would take on responsibilities formerly assumed by the government: ‘Government needs to be more restrained in its interventions in areas in which civil society can be expected to pick up issues and set norms’ (Etzioni 1993: 7). This, however, is difficult for governments because – in contrast to individual citizens who need little more than information to exercise their autonomy and choice – civil society needs to be both left alone to develop by itself *and* to be stimulated, developed, and nourished:

The most important and probably also the most difficult task for the government will be tempering its own ambitions. It will have to focus most of all on creating conditions and on guaranteeing procedures. [...] Modern government [...] needs to be more restrained in what it regulates, provide more room to citizens and organisations (Ministerie van Bestuurlijke Vernieuwing 2003: 6).

The following white paper in 2005 – *Exploring Citizenship and Different Government* (Ministerie van Bestuurlijke Vernieuwing 2005) – placed even more responsibility on citizens and civil society. It sought to make them responsible for the provision and management of services that were previously (also) considered government tasks. We need more reciprocity between government and citizens, the white paper argued; the relationship between citizens demanding services and governments providing them should be more balanced. Such reciprocity requires active citizenship:

[It] demands that citizens do indeed contribute, which implies an active attitude from their side. If citizens – as is more common in the classical idea – believe that they do not need to do anything that is not prescribed to them in detailed rules and regulation, then it [the desired reciprocity] does not work (*ibid.*: 9).

Citizens should be ‘held accountable on the basis of generally phrased norms and general rules of decent citizenship’ (*ibid.*: 11). The coalition agreement of 2007 contained plans for a *Charter for Responsible Citizenship*. But out of fear that it could appear paternalistic, the charter was to be formulated ‘in dialogue with citizens – although the terms are already set by the government itself. Citizens should debate four themes: respect, orientation towards the future, engagement and efforts for society’ (Ministerie van Binnenlandse Zaken en Koninkrijksrelaties 2009)

The WMO can be seen as the crowning achievement of government efforts to stimulate active citizenship; at its core lies the ideal of active citizens taking individual responsibility for themselves and others. As the Ministry of Health, Welfare and Sport explains:

The WMO is the result of broader policy, emphasising individual responsibility in healthcare. [...] The aim of the Social Support Act is the participation of all citizens in all facets of society, whether or not with help from friends, family or acquaintances (Ministerie van Volksgezondheid, Welzijn en Sport (2007).

Cost reduction is once again a key concern, and we see that much of the legal framework of the 1968 AWBZ legislation on long-term care has been replaced by a much weaker legal framework in which there are no individual rights to services but only a budget to be distributed among those who need it. While the AWBZ referred to individual legal entitlements, the WMO describes ‘areas of achievement’ for local governments without guaranteeing services to individual patients. What patients do or do not receive depends on the available funds and on local priorities in allocating this money. The move of care services from the AWBZ to the WMO also entails devolution from the national to the local level.

Active citizenship – in the form of informal care and volunteering – is deemed to be the solution to fill the gap resulting from this scaling back of rights. The WMO thus banks on the responsibility of informal care-givers and volunteers where paid care has already disappeared, or will soon do so.

This substantive reduction of rights was accepted with relatively little protest. While patients' organisations and local governments raised some concerns (and many amendments were prepared in parliament to respond to them), few of these had any substantial impact on the core of the law itself. The only potentially significant amendment was the legal right to be 'compensated' for handicaps that limit one's ability to participate in society, the so called 'compensation principle'.

Informal and professional care-givers, the two parties that could have protested, are politically and organisationally weak in the Netherlands. Professional care-givers had been framed as the enemies of patients in the Netherlands since the 1970s (Duyvendak 1999). In the three decades that followed, professionals were not in a position to raise their voices, neither as experts nor as defenders of patients' interests. Recent years, however, have witnessed a debate on the 'taming of professionals' in the public sector (Duyvendak *et al.* 2006; Tonkens 2008; Noordegraaf and Steijn 2010), with critics now arguing that professionals should be less imprisoned by bureaucratic regulations and allowed more discretionary power. The message resonated and was reflected in the central government's 2007 coalition agreement, which pleaded for 'more room for professionals' in the public sector (as this has yet to be translated into policy, the position of professionals in practice has hardly changed).

(Informal) care-givers' organisations are not very powerful in the Netherlands either. The dire financial circumstances of care-givers that necessitated their organisation in for example the UK was never the case in the Netherlands. Living in male breadwinner households and working on average few hours, most informal care-givers did not descend into poverty. The legal right to reduced working hours to allow time for care was one the victories of the women's movement.

What informal care-givers do demand is that their contribution to society be recognised and valued. Caring for loved ones oneself is highly valued in the Netherlands (Kremer 2007). In practice, the emphasis on citizen responsibility means greater pressure

on women's time and energy. This is not met with resistance so long as it comes with recognition of the value of (women's) care in the form of more time and financial compensation. The WMO recognises this. In the words of the former vice-minister and long-time feminist Jet Bussemaker:

Volunteers and care-givers make an important contribution to the self-reliance and participation of others. And they contribute to ... the social coherence of our society (Bussemaker 2007).

The WMO thus frames government withdrawal as leading to active citizenship:

Volunteers and carer-givers provide an example of 'active citizenship'. Participation in wider networks and the mutual involvement of citizens also have wider positive effects. They contribute to strong social cohesion, to a stable society and to democracy. [...] Care-givers and volunteers are actively involved citizens (*ibid.*).

Bussemaker proudly declares that 'the Netherlands leads the way when it comes to the percentage of citizens who voluntarily devote their time and energy' (*ibid.*). Nevertheless, recent research shows that volunteering has been declining since 1989 among all groups except those aged 65 and above (Dekker *et al.*: 79). The pride over volunteering can be seen as a plea for greater involvement and appeals to feelings many Dutch have consistently reported in recent surveys (SCP 2005) that they are happy with their own lives but unhappy with the wider society. The WMO appeals to this desire for community and promises a more caring, cohesive society.

Communitarian participation is thus a cornerstone of the WMO. While the ideal of citizen responsibility remains linked to government withdrawal, responsibility is now less delegated to individual citizens and more to citizens' collectives – the target has shifted from (women in) families towards (women in) neighbourhood collectives and civil society organisations.

Community care and networks of care

How does the WMO's ideal of responsible communitarian participation work in practice? Two recent studies we conducted shed some light on this.

The first study draws on the research project 'Living in the Community? Community Care for Psychiatric Patients and People with Intellectual Disabilities' (Verplanke and Duyvendak 2010). We conducted 67 in-depth interviews with psychiatric patients and people with intellectual disabilities living on their own in Dutch neighbourhoods. Most had previously spent considerable periods of their lives in large care institutions in the countryside; others with intellectual disabilities had lived with their parents.

The policy of deinstitutionalisation, ascendant in many Western countries over the past three decades, posited that it would be better for people with psychiatric and intellectual disabilities to be part of society and to live on their own in ordinary neighbourhoods. A warm and caring community would replace the coldness and isolation of their former institutional homes – this, at least, was the prognosis of the deinstitutionalists. Therefore a key question in our interviews was: How welcoming is the surrounding community? Do neighbours help you to participate in society?

The answers were sobering. The majority of the psychiatric patients and people with intellectual disabilities we interviewed live as solitary individuals in their communities. In general, they had very little, if any, contact with neighbours or other locals in their new neighbourhoods. Contact with neighbours was usually limited to saying hello and, at best, to brief chats on the street. There was hardly any deeper contact, for example drinking coffee together or helping each other with small tasks. Some interviewees mentioned unpleasant experiences with neighbours. A 31-year old woman with intellectual disabilities told us that not long after her move, she found bits of food on her doormat that had been stuffed through the letterbox. This happened at least five times. She was quite sure that it was one of her neighbours.

Those who visited our interviewees in their homes were mainly relatives and personal care-givers. Respondents looked forward to their daily or weekly visits when

they could talk about what was going on in their lives. For about 60% of respondents, the care-giver was ‘the most important person in my life’.

The WMO is an important law for psychiatric patients and people with intellectual disabilities living on their own, because for these people participation in the ‘normal’ community requires a great deal of special support. The WMO assumes that active citizens – family members, neighbours, volunteers – will take responsibility both for themselves and for others who need help to participate in society. But the experiences of the respondents in the research project ‘Living in the Community?’ hardly encourage optimism. They found the ‘normal’ community to be indifferent, sometimes even hostile. The crucial role of the personal care-giver in their lives is particularly troublesome as the WMO (unlike the AWBZ) recognises no legal right to this kind of care. To put it bluntly: whereas living on one’s own in the community has more or less become an obligation for people with psychiatric and intellectual disabilities, local governments are not obliged to care for them.

The second study examined patterns of cooperation within 25 networks of care around patients with various illnesses and handicaps (Tonkens *et al.* 2009). We conducted 75 in-depth interviews with patients, care-givers and professionals. Of the 25 networks we examined, only three fit the WMO’s ideal. These *balanced networks* included professionals, volunteers and informal care-givers. Crucially, one central informal care-giver arranged and coordinated all the care and volunteering, ensured effective communication within the network, made sure there was back-up care when needed, and that all those involved felt appreciated. To be able to do all this, she reduced her working hours, adapted her job to her care tasks, or stopped working altogether. Towards volunteers and other care-givers, this central informal care-giver is a ‘human resources manager’. She can be warm and comforting towards the patient, individual care-givers and volunteers, but firm and assertive towards organisations. She perceives formal care as a fundamental right and complains if the care provided by an organisation is inadequate. She is bureaucratically competent, speaks Dutch fluently, and is well-acquainted with the rules, regulations and institutions of the welfare state, usually through a (former) occupation in healthcare services. She is furthermore in a financial position to

reduce her working hours or to stop working altogether. It comes as no surprise that members of these networks were native Dutch with higher educations.

The other 22 networks were less well-attuned to the modernisation of welfare as embodied in the WMO: some networks relied heavily on family members, others on professionals. In the *family networks*, (mainly female) family members provided most of the care, while professional care was sometimes made use of on the side. Sometimes one family member performed all care tasks. There was little or no discussion on how tasks could be divided; the whole idea of negotiation, either with family members or with professionals, was strange to the main care-giver. With no support from others, the WMO simply meant that access to care services had become more difficult: services are less readily available and the care-giver, not feeling entitled, will not claim them. She does not know how to access professional care while her family members – considering care the family's responsibility – will not help her to find it. Most of these family networks consisted of immigrant families of Turkish or Moroccan descent.

At the other end of the continuum, we found *professional networks* in which professional care-givers perform most of the care tasks while (informal) care-givers help out on the side. All members of these networks felt that professional care had intrinsic value; contrary to the dominant opinion within family networks, professional care was not judged to be of lesser quality than family care. These professional networks are also ill-prepared for the WMO, as they often lack a central care-giver and are not prepared or able to coordinate and negotiate the responsibilities. Their members lack the capacity and time to perform these roles, and also assume the welfare state is there to support them in this. Care-givers in these networks do not expect much from their family or friends who, they argue, have their own lives and worries. But they do have high expectations of the welfare state and its professionals. Yet particularly those who care for patients with progressive or difficult and incurable diseases tend to feel let down. To do even more, to be responsible for arranging and coordinating all care – as care-givers in the balanced networks do – is stretching their capacities to breaking point. These networks consist mainly of native and Surinamese Dutch. The WMO does not fit their expectations or lifestyles, requiring them to be quite different from what they are.

Thus the WMO's modernisation of welfare – with its emphasis on informal care and cooperation between partners in care – is best attuned and most accessible to those who least need these services: people who are self-assertive, highly educated, bureaucratically competent, fluent in Dutch (and thus able to operate in balanced networks), and able to reduce their working hours. The WMO is ill-equipped for all other groups, though in varying degrees. It expects them to have capacities and views regarding care that they do not have – and thus marginalises them.

Citizen responsibility and/or government paternalism?

With the emphasis on citizens' responsibilities to participate in society, the spotlight is increasingly falling on those considered to be falling short of this ideal: people who live isolated in their own homes and those deemed not to be educating their children to become active members of society. The focus has been on immigrant mothers and families as well as people with behavioural and/or psychiatric problems. All are subject to outreach programmes where social workers try to 'get behind the front door' to identify social problems and to offer care and welfare, often employing both carrots and sticks. Social workers in some poorer areas even go door to door, encountering domestic violence against women and children, debt, educational neglect, illegal housing, the illegal growing of soft-drugs, and loneliness. Such visits by social workers reflect a more controlling and interventionist government.

These outreach programmes simultaneously hold all citizens responsible to a code of conduct and deem some citizens (still) incapable of managing their own lives. The approach is evident not only towards adolescents and people causing serious harm to others, but to legal adults not living up to the ideal of active citizenship – 'for their own good'. There is thus a fundamental tension between the greater responsibilities implicit in the active citizenship discourse and the paternalism it gives rise to. It's hardly surprising that government demands for greater citizen responsibility backed by punitive measures are often perceived by citizens as paternalism (Kampen 2010). Seen together, the

emphasis on citizen responsibility and paternalism bolster one another – the two can be seen as the other’s distorting mirror.

Conclusion

How did the communitarian ideals of caring for one’s family and community – so evident in the new law on social support, the WMO – come to be embraced in a country where the patients’ movement had so successfully demanded autonomy, choice and voice? What does this emphasis on communitarianism in the face of government withdrawal mean for vulnerable citizens in need of support?

Greater voice, choice and autonomy were indeed won by the patients’ movement, but not only as rights. They were embraced by the government as they could also be framed as duties. The WMO indeed values autonomy: the active citizen it envisions is not just a caring communitarian but also an autonomous, *self-steering* citizen capable of arranging and managing various kinds of formal and informal care. Autonomy is valued by the patients’ movement because it fits its self-image. But as research has shown, it is less attractive to other, more vulnerable citizens (Tonkens *et al.* 2009; Verplanke and Duyvendak 2010). But who speaks on their behalf? (Professional) care-giver’s organisations may do so in other countries, but in the Netherlands such groups are weak. Furthermore, interpreting the WMO’s communitarian ethic as citizens taking care of each other risks overlooking how people care for themselves. Due to fear of dependency, vulnerable citizens are often reluctant to ask for support (Linders 2010). So while the spirit of the WMO is largely communitarian, it may well have the effect of throwing each citizen back on him/herself as a self-reliant, autonomous individual.

Fostering communitarian participation is the main aim of the WMO, as it was for the government to delegate problems of management and cost reduction to citizens. But communitarianism also appeals to many citizens, including the majority of native Dutch who have grown unhappy with what they perceive to be a selfish, over-individualised society. Communitarianism appeals to their desire for social cohesion; the rhetorical praise lavished upon informal care-givers also appeals to segments of the women’s

movement. We furthermore saw that the emphasis on responsible participation is accompanied by a movement towards paternalism: the state will intervene where the community fails to reach.

The current political landscape is shaking up the balance of interests that maintained the communitarian consensus between government, citizens and the patients' movement. While the past decade witnessed a shift from individual towards collective responsibility at the national level, the latest trend is in the opposite direction. We thus see rising tensions between communitarian and liberal ideals, for example, diverging national and local priorities concerning citizen participation. The recently installed centre-right cabinet is less concerned with local communitarian aims such as fostering social cohesion; it instead places greater value on the freedom of citizens to choose their own welfare providers through PGBs, which it hopes to give legal weight. Nevertheless, the current libertarian-conservative cabinet has decided to scale back central financing of the WMO and is proposing to lower local expenditures on PGBs. Although there is consensus on the inevitability of major changes in the organisation of care, the announced government cutbacks face local opposition, with municipalities claiming the cuts will reduce their discretion and erode social support (VNG 2010). The cuts have led to the paradoxical situation of municipalities having to defend consumer choice, whereas their main concern in recent years has been the fostering of social solidarity. The question for the coming years will therefore be how municipalities will be able to uphold their communitarian ambitions in the political struggle over central expenditures on the WMO.

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