



# Boundary lines between private and public care; Living independently at home or in a home

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## About ETHOS

*ETHOS - Towards a European Theory Of Justice and fairness*, is a European Commission Horizon 2020 research project that seeks to provide building blocks for the development of an empirically informed European theory of justice and fairness. The project seeks to do so by:

- a) refining and deepening the knowledge on the European foundations of justice - both historically based and contemporary envisaged;
- b) enhancing awareness of mechanisms that impede the realisation of justice ideals as they are lived in contemporary Europe;
- c) advancing the understanding of the process of drawing and re-drawing of the boundaries of justice (fault lines); and
- d) providing guidance to politicians, policy makers, advocacies and other stakeholders on how to design and implement policies to reserve inequalities and prevent injustice.

ETHOS does not merely understand justice as an abstract moral ideal, that is universal and worth striving for. Rather, it is understood as a re-enacted and re-constructed "lived" experience. The experience is embedded in firm legal, political, moral, social, economic and cultural institutions that are geared to giving members of society what is their due.

In the ETHOS project, justice is studied as an interdependent relationship between the ideal of justice, and its real manifestation – as set in the highly complex institutions of modern European societies. The relationship between the normative and practical, the formal and informal, is acknowledged and critically assessed through a multi-disciplinary approach.

To enhance the formulation of an empirically-based theory of justice and fairness, ETHOS will explore the normative (ideal) underpinnings of justice and its practical realisation in four heuristically defined domains of justice - social justice, economic justice, political justice, and civil and symbolic justice. These domains are revealed in several spheres:

- a) philosophical and political tradition,
- b) legal framework,
- c) daily (bureaucratic) practice,
- d) current public debates, and
- e) the accounts of the vulnerable populations in six European countries (the Netherlands, the UK, Hungary, Austria, Portugal and Turkey).

The question of drawing boundaries and redrawing the fault-lines of justice permeates the entire investigation.

Alongside Utrecht University in the Netherlands who coordinate the project, five further research institutions cooperate. They are based in Austria (European Training and Research Centre for Human Rights and Democracy), Hungary (Central European University), Portugal (Centre for Social Studies), Turkey (Boğaziçi University), and the UK (University of Bristol). The research project lasts from January 2017 to December 2019

## Executive summary

This Deliverable 5.4 ETHOS' Workpackage 5, 'Justice as lived experience'. Its aim is to analyse the divide between the public and private domain as a fault line of justice in the area of social policy, with special focus on issues of moral obligations and (inter)dependency. It compliments Deliverable 5.3 that explicitly focused on the subjective experiences elderly and disabled persons and their caregivers who all might be vulnerable to injustice. Deliverable 5.3 drew on and sought to develop Capability Approaches/Theory to analyse the actions, understandings and relationships described in national case studies of support services for elderly and disabled people in private households. This Deliverable 5.4 intends to explore and analyse residential support services for elderly and disabled persons as presented in social policy discourse, care regulations and governance, and in labour conditions for care workers in residential settings.

This study aims to unravel the fault line of justice in the division of public and private domain of care, related moral obligations and the meaning of (inter)dependency. Crucial here is that the core concepts – the public and the private domain - have multi-fold meanings, are completely intertwined and hard to unravel. Other diffuse and complex central concepts are care, gender and (inter)dependency and categorizations of elderly and disabled people are not straightforward nor is the classification of their respective needs.

Therefore, the first part of the paper will focus on these central concepts and conclude with some propositions on recognitive, redistributive and representative justice in the domain of care for elderly and disabled people. From that part it is concluded that the focus explicitly will be on the most public form of care services, those offered in residential settings. Residential care unmistakably is a form of public care outside the private home supported by public resources. Criteria for the quality, accessibility and costs of residential care inform us on the boundary lines between public and private care as do the reforms intending to (de-) institutionalize care services. Nevertheless, each form of care is influenced by public care policies and ideas on what it means to need and use care, what it means to perform care work, and what are the moral obligations of various forms of care work for both care users and care givers?

The second part of the paper therefore analyses in what way boundary lines between care in the private home and residential care are drawn in EU and national care policies; what image of people in need of care is feeding these boundary lines, how are these facilitated, supported and regulated and what are the implications for care users and care givers/workers? The paper analyses EU programs focussing on two categories of people potentially in need of care, elderly and disabled persons, to understand how these needs are interpreted, what boundary lines are drawn between the needy and the not-needy, and if public resources available for those needs. Subsequently, it discusses commonalities and differences in residential care policy between our four European Member States. This part is based on papers and documents, ENEPRI reports on long-term care policies in the four countries and on the ETHOS country reports (D5.3).

The paper concludes by identifying two antagonistic normative discourses. The first discourse creates an opposition between residential care and care at home, the second one contradicts dependency versus independency. Both oppositions go along with moral imperatives on what is 'right' and what is 'good', but mainly seen from the perspective of

the care recipient, less so from the perspective of the care worker. What is lacking is a specific vision of redistributive and recognitive justice in which the shared needs and interests and rights of care recipients and care workers can be defined as matter of interdependency that justifies a common good. The policy recommendations with which the paper concludes go beyond the boundary lines that define the antagonistic discourses. First, we plea for an unbroken chain of care in the form of a stepwise regulated, affordable and assessment-based care from the very light forms of care (housekeeping assistance) to more severe forms of care (care and nursing at home paid for by mandatory health insurance) and the most intensive form of care (individualized residential). Crucial is that no matter the institutional setting interdependency between care receiver and care worker is recognized and guaranteed. Second, for care workers in home care and in residential care working conditions, social protection and job satisfaction should be guaranteed. Thick boundary lines between residential care and home care still hamper recognitive and redistributive justice in both localities. Restoring the care chain by a stepwise connection of care at home and care in homes is morally and efficiently imperative in recognizing and redistributing interdependent justice.

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## List of Abbreviations

AMvB = Algemene Maatregel van Bestuur (General Government Decision)

BIG = [Wet op de] Beroepen in de Individuele Gezondheidszorg (Dutch Act on Professions in Individual Healthcare)

EASPD = European Association of Service providers for Persons with Disabilities

EC = European Commission

EDF = European Disability Forum

EEG = European Expert Group

EU = European Union

GDP = Gross Domestic Product

IPSS = Private Institutions for Social Solidarity (Portuguese: Instituições Particulares de Solidariedade Social)

LTC = Long-Term Care

MS = Multiple Sclerosis

NGO = Non-Governmental Organisation

OECD = Organisation for Economic Cooperation and Development

OOPOEH = Opa's en Oma's Passen Op Een Hond (Grandfathers and Grandmothers Care for a Dog)

PGB = Persoonsgebonden Budget (Dutch cash-for-care system)

RSE = Residential Structure for the Elderly (Austrian)

UN = United Nations

UNCRPD = UN Convention on the Rights of Persons with Disabilities

WLZ = Wet Langdurige Zorg (Dutch Act on Long-term Care)

## Tables

Table 1: overview care relationships in ethnographies.

Table 2: initiators/promoters of Active Ageing projects 2012

Table 3: Character of Active Ageing projects 2012

## Introduction

This study aims to unravel the fault line of justice in the division of public and private domain of care, related moral obligations and the meaning of (inter)dependency. Crucial here is that the core concepts – the public and the private domain - have multi-fold meanings, are completely intertwined and hard to unravel. Other diffuse and complex central concepts are care, gender and (inter)dependency, categorizations of elderly and disabled people are not straightforward nor is the classification of their respective needs. Therefore, the first part of the paper will focus on these central concepts and conclude with some propositions on recognitive, redistributive and representative justice in the domain of care for elderly and disabled people.

In D5.3 (Anderson, 2018) the Capability Approach is applied in analysing redistributive and recognitive justice in home care for disabled and elderly persons in need of care. There the focus has been on time and mobility as possible impairments of living a good decent and dignified life. It is concluded that: “Applying Capability Theory to relations of personal assistance and care suggests the fruitfulness of taking as a starting point what people consider to be a life they have reason to value.” (ibid: 30) The report shows the political and policy limits and possibilities of redistributive justice to the formation of decent capability sets that can easily be bypassed by people with higher incomes, better communication skills and social networks. The claim for redistributive justice is also clearly formulated from the side of the care workers concerning their own workload, proper wages and contracts but also on behalf of the time resources available to deliver good care at home for the people in need of it. Applying Capability Theory in that report also highlights the importance of recognitive justice as an expression of mutual respect between care workers and care users. In ‘seeing’ and ‘appreciating’ each other as valuable human beings open communication and transparency are fruitful means to avoid or resolve potential conflicts. The latter however is not applicable in all instances; if independency of the service users is prioritized invisibilisation of the personal assistant as well as strict guidelines for do’s and don’ts are in place. Anderson (2018: 30) therefore wonders:

*‘[H]ow to scale up from these answers, which may in some cases be expressions of personal preference, to questions of justice. That is, how does one move from a commitment to concrete and particular concerns to broader social and political demands? This is precisely what Nussbaum’s list of central human functionings claims to do. Indeed, in the context of the national case studies many of the functionings that figure on this list seem highly relevant, particularly those that capture emotion and affiliation, which give us a vocabulary to legitimate these claims. As illustrated by the ‘part of the family’ model of caregiving, the principal concept that we currently have for legitimating these claims is the family, yet this does not adequately capture the complex webs of affiliation and emotional connection we are woven into or excluded from.’*

In this D5.4 paper we move on by focusing on the boundary lines between the public and the private domain and the redistributive and recognitive justice principles that are applied to distinguish both domains as prevalent spheres of care. As we shall see also in care policy reforms the family model is a driving force, albeit that it is hidden behind the screens of ‘independent living’. Care at home is the hegemonic paradigm paradoxically associated with the moral imperative of care receiver’s independency, free choice and self-responsibility that not only disregards care users’ dependency on

the community, social network and family members but also hides the moral obligations for unpaid and underpaid caregivers, who are in majority unpaid female family members and migrant care workers. The turn towards de-institutionalisation related to the paradigmatic shift towards 'Independent Living' is not unproblematic from the perspective of redistributive and recognitive justice. It affects care recipients, elderly as well as disabled persons whose access to residential care is limited and it has consequences for unpaid and underpaid caregivers being in place as substitutes for professional care work. This paradigm might be hegemonic but a contrasting discourse is present as well represented by the social investment paradigm that in contrast pleads for institutionalization of care on behalf of women's employment, efficiency and limiting family dependency. In the conclusions it will be seen what alternative vocabularies and practices are available for rethinking boundary lines between public and private care. As a starting point however, the paper contests the private-public binary itself because of the lack of clear-cut boundary lines between the two domains.

In this D5.4 the focus will be explicitly on the most public form of care services, those offered in residential settings. Residential care unmistakably is a form of public care outside the private home supported by public resources. Criteria for the quality, accessibility and costs of residential care inform us on the boundary lines between public and private care and their moral imperatives as do the reforms intending to de-institutionalize care services. Here we take into consideration that each form of care is influenced by public care policies and ideas on what it means to need and use care and what it means to perform care work. The main questions then are in what way boundary lines between care in the private home and residential care are drawn in EU and national care policies; what image of people in need of care is feeding these boundary lines, how are these facilitated, supported and regulated and what are the implications for care users and care givers/workers? After the conceptual reflections the paper analyses EU programs focussing on two categories of people potentially in need of care, elderly and disabled persons, to understand how these needs are interpreted, what boundary lines are drawn between the needy and the not-needy, and if public resources available for those needs. Subsequently, national care policies will be discussed to understand commonalities and differences in residential care policy between our four European Member States. This part is based on papers and documents, ENEPRI reports on long-term care policies in the four countries and on the ETHOS country reports (D5.3). In the ethnographies presented in D5.3 and the respective country reports of Austria, Hungary, the Netherlands and Portugal six variants of care relationships have been observed, of which only one is situated in a residential setting.

Table 1: overview care relationships in ethnographies.

	Private home	Residential
Publicly subsidized	<ul style="list-style-type: none"> <li>- Professional, permanent contract (NL, Portugal)</li> <li>- Unskilled, non-permanent contract (Austria)</li> </ul>	<ul style="list-style-type: none"> <li>- Professional, permanent contract (Portugal)</li> </ul>
Privately paid	<ul style="list-style-type: none"> <li>- Unskilled, live-in migrant worker (Turkey)</li> <li>- Unskilled, pensioners (Hungary)</li> <li>- Professional, paid by service (Hungary)</li> </ul>	

Nevertheless, in all ethnographies the meaning of receiving care at home versus in a residential setting is reflected on. In cases where care at home is meeting the needs to the satisfaction of the care users residential care is pictured as the worst thinkable option while it is imagined as a good alternative in cases where good quality care at home is hardly available. The evaluation of residential care however is not only dependent on whether an alternative is offered. It also depends on the quality of residential care, the degree of dependency of the care user and maybe even more on the hegemonic care discourse in the respective countries.

In the analysis of boundary lines between public and private care we came across two issues connecting recognitive and redistributive justice claims. One is the independence-dependence axe interpreting and defining the needs and moral obligations of care users vis-à-vis care providers and care givers. The other one is the availability of public versus private resources available for meeting care needs. These resources pertain financial means as well as localities, that is places in residential care, and the quality of care work. In their turn these issues relate to the recognition of care workers (autonomy, discretion) and their working conditions (payments, respite, working hours and social protection).

Interestingly in this study is the struggle at all levels of governance with both axes. At the European level the debate on the interpretation of needs for vulnerable older and disabled persons is ambivalent and inconclusive. On the one hand there is the claim for expanding public investment in formal LTC services while other silos of the EU focus on active ageing and independent living as contributions to prevent the use of such services. At the national level we see some integrated LTC services combining rather well-arranged care facilities ranging from public resources for care at home to residential care. However, we mainly reckon rather fragmented care facilities and everywhere the number of places in residential care fall short in meeting the demand.

## **PART I: Contested boundary lines between private and public care**

In D5.3 the focus was on *paid care* in the private home thus excluding the fully private, informal and unpaid (often familial) care relations between care giver and care user. Whether paid care can be called private depends on the perspective taken. In the days of early feminist scholarship on care, for instance Wareness (1984) and with her Ungerson (1990) draw the boundary line between private and public care in the degree of particularism in care giving. This implies that they saw private care in which the care giver is relatively free to decide how and when to do the care-giving work (Ungerson, 1997: 15). Since those days the position of the care user has become much more recognized and valued while the decision making power of the care giver has become contested as potentially patronizing. In addition and due to the introduction of care allowances and cash-for-care systems, care in the private home cannot be claimed any longer to be purely private. It is often and in many countries paid for by public means, regulated by policy guidelines or directives and provided by professionals employed by (semi-)public organisations (Daly and Lewis, 2000; Knijn and Kremer, 1997; Knijn and Verhagen, 2007; Ungerson and Yeandle, 2007). Moreover, if care work is mainly family-based and thus a full-fledge private activity this often is the result of public care policies, namely its default (Kremer, 2007; Saraceno and Keck, 2008) affecting society at large and women in particular. Although it is still the main source of care in all countries included in this paper (Austria, Hungary, the Netherlands, Portugal and Turkey), the adversities of relying on unpaid female familial

care cannot be denied if only for demographic reasons, mobility of family members and women's labour market participation. Or as a Dutch care worker states with some nostalgia:

*Society is moving in a direction in which we will be working more and more with informal care providers, which is very difficult, because on the other hand, you are expected to move for your job. Before, Dutch culture [and society was organized] in a way that you would all stay together and you would take care of each other. Women worked less, so care was already a joint effort. And that is not feasible today, people no longer live together in the neighbourhood, so they can no longer mean much to their children, the children are getting older so they themselves will become grandparents and they will have their own obligations again. That is where you see a gap and that is why we [home care providers] provide care. (Interview with Selma, personal healthcare auxiliary)*

Also the European Commission (2013) in its report on long-term care (LTC) recognizes drawbacks of relying on unpaid informal care that is dominant in a minority of Member States but substantial in all Member States. After mentioning as an advantage the seemingly low public costs, the lack of public responsibility for financing, delivering and organising long-term care as well as the familial and probable good quality of care provided by closely related, well-intended and trustworthy carers, it points at major drawbacks of this care model:

*'[T]he near absence of direct public expenditure does not mean that family care is free. It comes at significant cost to families (i.e. primarily women as spouses, daughters or daughters-in-law) in terms of the working time of the carer, alternative employment income foregone and reduced accrual of social protection entitlements. There may also be out-of-pocket payments for care tools and assistive devices. The principle that every family is expected to care for its own family members also implies that there is no sharing of the burden/cost of care across families. In this approach, there is no pooling of the long-term care risk. Those with relatives in need of care do not receive any public support. Those with ageing relatives that can manage without LTC do not share in the societal LTC burden. The rights of older people in need of LTC will therefore depend on the ability and willingness of their families to provide them with care. There are few, if any, means to influence the quality and appropriateness of care that untrained informal carers provide. Neither the quality nor the sufficiency of informal care can be guaranteed. Neglect and even abuse may occur for lack of family resources to provide care, or as an unintended consequence when family carers are exposed to the physical and mental stress of being alone with care duties and to the social hardship this may involve.'* (European Commission, 2013: 13)

In evaluating other long-term care models, the EC concludes that also alternative models have their drawbacks. For instance, private out-of-pocket payments for substitute informal care workers result in the involvement of undeclared work by mainly illegal female immigrants in precarious jobs. Moreover, this model does not guarantee good quality care and brings indirect costs in taxes foregone. Inspired by the 'social investment approach' (see Morel, Palier and Palme, 2012), two other LTC models are presented as good alternatives; providing public support to family carers by way of care allowances, care leave or social protection schemes and replacing informal with formal care in various models of LTC financing and delivery. A conclusion of the EC is that current LTC policies in Member States differ widely in terms of risk pooling and equity in access as well as in their

capacity to optimise the quality and efficiency of care delivery. In particular the family care model fails on these key dimensions of care provision. Higher public expenditure on formal services will on the one hand make hitherto hidden costs visible, and social protection to cover long-term care will result in more equal sharing of the risks of disability in old age.

*'Importantly, it will not be possible to ensure equality of access to long-term care, guarantee its quality or develop productivity unless most of the current informal care is lifted into the formal sector.'* (ibid: 15)

Indeed, for reason of gender-equality, efficiency and cost reduction formalizing care for elderly and disabled persons might be a favourable option. However, Hochschild already in 1995 warned for cold-modern as well as post-modern models of care substituting the traditional female family care giver. The post-modern model in her description celebrates the independence of a person in need, being it a young child, an elderly or a disabled person. She already 30 years ago pointed at the elderly increasing portrayed as 'content on their own' under the condition of being equipped with electronical devices for emergency cases. In that post-modern model, according to Hochschild (ibid: 339):

*'We legitimize the care deficit by reducing the range of ideas about what a [person in need of care] „really needs” to thrive. Indeed the words „thrive” and „needs” go out of fashion, replaced by thinner more restrictive notions of human well-being.'*

The cold-modern model also does not offer much of an alternative in Hochschild's opinion. It is based on institutionalized care for maximum hours and institutional control. In such a model (analogous to the Soviet day care centres) the tension is between would-be and actual care, leaving out kin to get involved and care users to have a say. What remains is – of course – the warm-modern model of care including public institutions mixed up with sharing caregiving by women and men alike for their kin and close friends on basis of time schedules in work places, affordable institutional care and the valuing of care needs and care work (Hochschild, 1995). Hochschild is not very precise in her description of this warm-model of care, and it is obvious that not everywhere and for every person such a combination of needs and interests can be put in practice. Nonetheless, the model ideally could inspire redistributive justice claims (sharing between private and public domains, between the workplace and the private family, between men and women, and between needs and interests of care users and care givers). Also cognitive justice claims can be affected such as the valuing of care needs and their interpretation beyond the limits of efficiency and independency.

Deliberation on what care needs are and how these should be supported remains despite the 2013 EC report a contested policy issue even more when it concerns the formal setting of residential care. As we shall see the care discourse tends to praise care at home and to devalue institutionalized formal care. This de-institutionalization rhetoric does not translate immediately and everywhere in a reduction of residential places. In contrast most countries have expanded the number of places in residential care, albeit insufficiently to meet the demand. The rhetoric however seems to have stagnating effects on the wider expansion of the sector in times of austerity when governments look for arguments to reduce public spending. Therefore, we will come back on the adverse effects of de-institutionalization of care on blurring the boundary lines between the public and the private domain of care at the end of this paper. We will see that the way these domains of care are confused is

affected by the articulation of care needs in public policy and the path-dependent institutionalization of care services. Also national and EU level care and gender policy are influential as are recent reforms inspired by austerity and the public choice approach. Consequently, the diffuse boundary lines between the public and the private domain are completely permeated by redistributive policies, financial systems and moral approaches affecting the multiple interpretations of justice of care in the sphere of the public, the political and the personal.

### *Fragile private care; vulnerability and surveillance*

Late modern critical thinking contests schematic, systemic and cultural boundary lines between the public and private domain due to public exposure and regularly governance of private life, and neo-liberal reforms resulting in austerity measures shifting public goods to private sectors. The critical literature strand on late modernity challenges the strict borderlines between the public sphere associated with bureaucratic rules, administrative regulation and impersonal relationships on the one hand and private sphere associated with the informal, spontaneous and personal relationships on the other hand (Sennett, 1974; Giddens, 1991). In line with Riesman's analysis of 'other-directness' implying -among others – false personalization in otherwise patronizing work relations (Riesman, 1961: 265), Sennett argues that the spread of intimacy and even narcissism has effaced and eroded 'the Res Publica by the belief that social meanings are generated by the feelings of human individuals' (1974: 339), thereby undermining the impersonal, distant and coherent public space. Sennett disclaims intimacy and the value of close relations as inspirators for moral values in public life. In contrast he states:

*'The expectations are that when relations are close, they are warm; it is an intense kind of sociability which people seek out in attempting to remove the barriers to intimate contact, but this expectation is defeated by the act. The closer people come, the less sociable, the more painful, the more fratricidal their relations.'* (1974: 338).

Conversely, he celebrates distance and impersonality in the public relations to maintain clear boundaries between employers and employees, citizens and public servants and between politics and the personal. The risk of pretending intimacy in employer-employee relations may result in vulnerability of employees. Riesman formulates it even more stringent:

*'The personalization is false, even where it is not exploitative, because of its compulsory character: like the antagonistic cooperation of which it forms part, it is a mandate for manipulation and self-manipulation among those in the white-collar ranks and above.'* (ibid: 265)

In our days the risks of personalization in employer-employee relations in private care contracts also below the level of white-collar ranks are well-illustrated in the Turkish ETHOS country report (Akkan and Serim, 2018). Here five ethnographies are evaluated, three of which exemplify how fragile, though not yet fratricidal, personalized intimate care work by live-in non-kin workers can be:

Case 1: *'The employer, Fahriye asserts that they had certain problems with previous caregivers. Before her father died, a caregiver was providing care for both her father and mother. Her father had an Alzheimer disease and caregiver abused his state of illness. For example, her father was encouraged to give money for every service that the caregiver*

*provides. When she takes the meals, he gives money to her, when she gives his medicines, he again gives money to her although she has a regular monthly salary. Fahriye realized the situation and warned the caregiver about taking the money from his father. However, caregiver asserted that "it is normal, he gives her money as a gift and she accepts it. It is not a big deal." Then, Fahriye fired her and found a new caregiver. Fahriye did not speak of these things openly since she began to cry when she remembers it.'*

*Case 2: 'As he also underlined during the interviews, they also had problems with the previous caregiver. They were little problems but they damaged the relationship between Hamdi (the care user) and caregiver.'*

*Case 3: 'Leman and Sinasi [were] confronted problems with the previous caregivers. They went abroad to visit their older child. At that moment, the caregiver stayed at home alone and talked with the family in their home country on the phone. Sinasi saw that the phone bill was very high at the end of the month. When they got back from the vacation, they were upset and the job of the caregiver was terminated.'*

The other side of the coin is represented by Foucault (1978) and Donzelot (1979) as well as Habermas (1987), though on different grounds and with different moral impetus. They conclude that in the process of modernization an inversion of the private domain is going on by the intervening power of public systems. Foucault and Donzelot argue that driven by medical, demographic or psychological science-based bio-politics interventions and reforms install increasing control people's lives, attitudes, behaviour and manners. In that process bodies, minds, familial and social relations are transformed into productive forces fitting in modern regulative systems. Habermas (1987), although distancing himself from the nihilist perspective of Foucault on power relations and freedom, notes that the distinction between system and life-world is becoming diffuse because all kind of public systems are increasingly permeating the life-world; state regulations, categorizations of people under surveillance and the monitoring of people's intimate lives have become daily practice as part of public provisions. An example can be found in the Dutch home care system promoting citizens in need to assert their own strengths and possibilities. For that purpose monitoring instruments are introduced such as the 'Self-sufficiency Matrix' and the 'Participation Ladder'. Care providers and citizens alike assume these instruments creating an illusory picture of measurability and controllability, especially among vulnerable groups. In line with this, some policy staff and providers are unconvinced about whether progress in achieving independence and participation can be measured at all and warn about the danger of going too far in promoting independence and participation (Knijn and Hiah, 2018). An alternative and purely private regulation and monitoring of care work (in this case called 'personal assistance') we find in the Austrian ETHOS country report (Meier, 2018: 17). Here:

*'The service users in case 2 draw a lot of attention to not mix up private life, friendship and personal assistance. They draw a strict line between work and private life. They adopt a rather strict leadership style and set of about 52 written rules, which they submit to all personal assistants at the beginning of every month. In case a rule is violated, the violator will receive a verbal rule-reminder, in case a rule is not obeyed because it was formulated in a misleading manner, the rule will be revised and submitted to all assistants again. The set of rules is permanently updated based on experiences with the assistants.'*

Giddens (1991) reflects on the blurring of the borderlines between the private and the public sphere by accentuating among others the transformation of time and space that have opened up potential social relations over wide spans of time-space. Social relations in late modernity are disembodied by abstract systems and interpenetrated by the local as well the global resulting in the diffusion of the modern distinction between self (the private sphere) and society (the public sphere). A prosaic illustration of such blurring lines between the public and the private is presented by Hochschild (1997) showing that American workers today find a personal social life and dear friends at the workplace while their family home is regulated by a strict and almost rigid time regime. Hence, a main issue in regards of care in the private domain is finding a balance between avoiding surveillance and over-regulation as a mean to control every aspect of the care relation, either in private or public contracts on the one hand, and on the other hand avoiding arbitrariness by pretending a familialist personal relationship between care workers and care users who actually are employees and employers.

#### *The mixture of public and private care*

Neo-liberal reforms have contributed to the institutional blurring of the public and the private domain. The post-war literature distinguished two forms of public spheres; the state and civic society as well as two private spheres; the market and the family/community (see Jenson and Saint Martin's welfare diamond, 2003, as an extension of the welfare triangle of Esping-Andersen, 1990). A main question in care-related welfare regimes literature is which sphere is responsible for what care service and what are consequences for social protection, social citizenship, the fulfilment of needs, and gender equality? Feminist studies in the 1980s concluded that the concept of care is mostly absent in the public debate on citizenship, that most care work is on the shoulders of unpaid female family members, that care services are only marginally included in the public sphere and are hardly defined as public goods for which governments take responsibility. If at all, a sharp distinction was made in public systems between care for children and care for disabled and/or elderly persons. Except for the Northern European countries care work has been mainly situated by fault or default in the private sphere, were extremely gender-inequal divided and in the hands of female family members in the post-war decades (Saraceno and Keck, 2008). These boundary lines began to shift at the end of the previous century because of the increase of women's labour market participation and the consequential risk of a shortage of unpaid family caregivers. At the same time the need for a second income in households emerged because wages stagnated. In response cash-for-care systems have been introduced in many European countries to compensate for the unpaid care work for female caregivers, although to various degrees of generosity. Gradually cash-for care systems have been introduced to commodify private and familial care relations, some of which accompanied by regulatory systems and public governance of the private sphere. In the same vein neo-liberal reforms inverted another boundary line between publicly and privately provided services. Inspired by New Public Management thinking governments decided that for reasons of efficiency and in order to promote 'public choice' commercial actors would be better equipped to offer care services to the users. Again, the way and the degree of outsourcing care services to private corporates vary per country with some countries taking the lead, like the Netherlands and the UK.

In *Public or Private Goods?* Unger et al., (2017: 8) suggest three justifications for government intervention in any activity or good; equity, moral concerns or efficiency reasons. The 'right' justification has implications for the trade-off between equity and efficiency. Public intervention in

any good or activity, such as care, can according to Unger et al., (2017) be justified for reasons of *redistribution* as market forces would result in democratically unacceptable levels of unequal care provision. It can also be justified by *moral reasons* if it concerns goods that for moral reasons not should be commodified, that is exchanged as priced demand-supply goods. The final reason is *efficiency* implying that the public sector outperforms the market in producing (the quality) of such goods. Government intervention in the provision of care can however take many shapes and be organized in various ways. On basis of a range of studies in various sectors and several European countries Unger et al. (2017: 281) conclude, with Leibfried et al. (2015) that the state remains a key actor in many areas of social and economic life, although not as a provider of public goods. Instead the role of the state has shifted to a financier of public tasks and goods while it keeps its regulatory power, or even has extended that power with respect to the increasing role of markets as providers. In the domain of care, we therefore analyse the institutional blurring of the public and the private domain by distinguishing between the provider, the regulator and the financier of care. Do we see a shift from public to private provision of care either to the family or the market, and who then is regulating or financing care for elderly and disabled people?

### *Setting, resources and regulations of care*

The domain of care first refers to the institutional setting in which care is provided. The simplest and most prosaic distinction is the one between care at home versus residential care (elderly and nursery homes, hospital and homes for disabled persons). Such an institutional distinction not per se overlaps with a divide between impersonal, bureaucratic and administered public care on the one hand and personal, informal and spontaneous private care. As written above institutional care can be either warm and empathic or cold and distanced, offer high quality, committed and personal care or efficient, low quality, impersonal and undedicated service. Moreover, the role of private actors in residential homes should not be underestimated; private actors like family members and volunteers as well as private companies may contribute substantially to residential care service. Also, the association between private care and high quality warm and involved relationship should not be taken for granted. In private care as Sennett seems to indicate and many studies on familial care confirm intimacy might become a burden for care users and care givers alike due to arbitrary, painful, negligent and even abusive care relations. Regarding the institutional setting (at home or residential) of care individual preferences are historical dynamic and context dependent. As we have seen in D5.3 *recognitive justice* in home care depends on the experienced feeling of dignity, being respected and being capable of living the life one chooses. It can be assumed that the same goes for people living in a residential setting.

Secondly, paid care at home like residential care often is publicly financed. Although the majority of care at home is still performed by unpaid family members, increasingly home care is delivered 'in kind' by professional workers in public service or by formal or informal care workers who are paid by publicly funded cash-for-care systems. Residential care depends mainly on public resources but out-of-pocket money and income related personal contributions remain relevant. Conversely, the costs of commercial residential care services might be fully or partly covered by public finances (via taxation or compulsory health insurance). Alternatively, if public financing for care is limited, costs for – home care and residential care – are mainly financed privately. Here *redistributive justice* principles are at stake because of scarce public resources divided among an increasing ageing population. Questions of who is eligible for what kind of care on basis of what kind of care needs but

also issues related to payments and time for care work challenge the relationship between the right to care as a public good and criteria as efficiency and morality of care services.

A third boundary line concerns the role of the state as a regulatory agent. Is privately provided care (by the market, kin or volunteers) an unregulated formal or informal market or does the state regulate, monitor and control care services that in some countries have developed into care markets? Do governments set criteria for eligibility and if so, what are the boundary lines for eligibility and access, are qualifications, working conditions and payments for care workers defined and are these similar for home care and residential care? But also, what does it mean for care workers and care users if the state does not regulate home care? Does this imply that redistributive and recognitive justice principles are pronounced, are care users better able to realize their capabilities and preferences without public interference, and what are the implications for care workers?

Hence, the domains of private and public care are not oppositional and mainly operate in combination in home care, less so in residential care. Questioning boundary lines between public and private care therefore involve issues related to the interpretation of needs, the preferred institutional setting in which those needs can be fulfilled, and the resources available. It also contains questions of access, affordability and quality of care services in different settings and its effects on the free choice for it. Finally, it comprises aspects of the care work, the latter including payments and working conditions. The interpretation of care needs is a crucial though contested determinant in care policies. Fraser (1989: 294-295) outlines the complex character of needs interpretation by sketching the diverse and often contradictory narratives of needs interpretation that is also applicable to care needs. She distinguishes five narratives struggling for priority of which for our purpose we select 1) The officially recognized idioms in which one can press claims; for example, needs-talk, rights-talk, and interests-talk, and 2) Modes of subjectification; the ways in which various discourses position the people to whom they are addressed as specific sorts of subjects endowed with specific sorts of capacities for action; for example, as "normal" or "deviant," as causally conditioned or freely self-determining, as victims or as potential activists, and as unique individuals or as members of social groups.

We will focus on the idioms in which care users and care workers juxtapose their care claims vis-à-vis each other, the government and care providing organisations as well as the interpretation of care needs in the official idiom of the political discourse in the European Union and Member States. In doing so we will elaborate the way these idioms construct social identities of people in need of care and of care givers.

## Care policy

The definition of care policy in this study refers to principles that govern state-driven action directed towards given ends in fulfilling care needs and interests. It implies the definition of outcomes and the means, processes and resources to realize these outcomes. Social policy inherently is about reforms that answer to changing demographic, economic and political situations, and formulate criteria for expected or wanted changes in systems, practices and behaviour. It anticipates on the idea of a 'good society' and redefines the criteria of what it means to aim for it by referring to the 'collective will'; it is the people who ask for it. Of course, that collective will is imaginative and created, so we will see

how its represented at the EU policy documents elderly and disabled persons and their care needs. In addition, social policies govern action by not only articulating the needs for care and by categorizing those whose needs deserve to be fulfilled or supported but also by defining the institutional setting of who should provide it. Social policy research therefore questions the who (eligibility criteria plus categories of the population), the what (benefits, services, resources) and the methods (provisions, processes and conditions) of state-driven actions to realize certain outcomes. Moreover, social policy research also raises the question of why, that is what is the function of the specific policy? As Titmuss (1968) outlines in *Commitment to Welfare* such functions may be multiple and include compensation for disservices, for unmerited restrictions due to handicap or age, protection of society against malfunctional persons, investments in the future, promoting personal well-being or a mere contribution to economic prosperity. In the welfare mix of the market driven European social policy discourse the issue of what is 'private' (family, community) in contrast to what is 'public' (state, civic society) care is a topical matter of justice, even more so because of the parallel EU gender-equality paradigm that so far did not succeed in establishing gender-equal warm-modern care for the vulnerable populations depending on care.

### *Conceptualizing Care*

Mainly feminist scholars unravelled, analysed and conceptualized the prosaic daily and taken for granted activity that is called 'care'. Theorizing care cannot do without theorizing premises of gender, the unequal gendered division of care work and vice versa. Studies on care from a gender perspective criticise the dominant political philosophical approach of justice for its failure to understand the binary of dependence and independence as well as the distinction of public and private (Benhabib, 1986; Fraser and Gordon, 1994). Care is a complex and contested concept at the level of political philosophy, sociology, social policy and in daily life too. It is central in defining justice precisely because it is associated with the needs of vulnerable people, children, and disabled and elderly persons as care users and with women as taken for granted though low-status care givers. To overcome these prominent associations this paper is inspired by though not strictly follows the holistic approach of care as formulated by Tronto and Fisher (1990) who define care as a concept that goes far beyond the daily activity of supporting people in need but encompasses the entire globe:

*'On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web.'* (Tronto and Fisher, 1990: 40).

Tronto and Fisher distinguish four phases of care. *Caring about*, that involves recognizing a need for care and means feeling committed to the needs of every vulnerable person, whether it is a friend, a family member or someone at the other end of the globe. Caring about in the perception of Tronto and Fisher is not limited to individuals and might also involve the needs of other species, though it does not typically involve an active commitment or purposeful behaviour to fulfil the recognized need; caring about belongs to the domain of attitudes, sentiments and feelings that can be comforted by various means; an expression of commitment might do, such as for instance a statement by the European Union that is not followed up by concrete actions. In the private sphere it

might mean expressing concerns about someone's needs but not acting accordingly. *Caring for* in contrast implies taking responsibility to meet the recognized need by an active organization of addressing the need; facilitating care provisions, managing care work, facilitating care services or subsidizing care workers and organizing a care network are examples of caring for. At the political level this might mean facilitating care services, subsidizing care work or expanding home care budgets. Private forms of caring for might involve organising a network of care for a family member, supporting people in need of care to find a proper care worker or solving the administrative burden of the cash-for-care system for a care user. *Care giving* exists in the real work according to Tronto and Fisher (1990); the actual physical work of providing care, nursing, housekeeping, washing the baby or the patient, giving attention and emotional support, a helping hand and psychological guidance, all make up this intensive relational and physical aspect of care. People performing the caregiving operate both in the public sphere as professional care workers in residential and home care but in majority they are paid or unpaid female family members and paid - migrant - workers performing the job in the private home. Finally, they distinguish *care receiving*, an aspect of care that stands a bit aside the first three aspects of care because it refers to the evaluation of how well the care provided meets the caring need. Care receiving starts from the point of view of the person in need of care who from her/his perspective qualifies if and how other people care about, care for and give care.

Although Tronto and Fisher (1990) and Tronto in her later publication (1993) are attached to an ethics of care that is holistic and encompasses a global orientation including climate change, thus do not want to narrow down the care concept to care relationships between individuals in need of care and those who care for them, Tronto (1993) nevertheless has put much attention to direct and relational care activities. This paper will do the same.

#### *Care and interdependency; the moral obligations*

Most people associate care with fulfilling the needs of people who obviously are in need of care; babies and children, elderly and physically and mentally disabled people and maybe also included are people who are unable to live a decent life without support due to bad luck or unforeseen circumstances; the homeless, the poor or refugees. An issue is whether people in need of care are seen as deviating from normal people, if their life is seen as abnormal or that having need of care belongs to the normal human condition somewhere during the life course. Is being dependent on other human beings a fact of life and if so to what extent? Is a normal human being an able autonomous self-responsible person who doesn't need any support, an atom surrounded by other atoms? For instance, Kittay comments on equality theories such as that of Rawls because of its assumption that a society is composed of equal and autonomous persons:

*'Political philosophers who advocated equality always have presumed that all members of a society are or ought to be equals. And yet my daughter [who suffers from cerebral palsy] can never be an equal in the sense in which political philosophers speak of equality (...) in the sense of an autonomous and equally situated or empowered individual, even within the well-ordered society contemplated by the egalitarian liberalism of John Rawls. This is to say that dependency here is fundamental and is not merely a descriptive feature of a non-ideal social order. It must be included even in the norm of an ideal social order'* (Kittay 1998:36).

Despite this comment on egalitarian liberalism the fundamental binary of dependency and independency is still present in this quotation, Kittay just asks for recognition of dependency and the related care work that stands in the way of becoming an autonomous and empowered person. We go a step further by challenging the binary itself. First, such a binary denies the vulnerability of every human being and excludes from the imagination of dependency - in political philosophy and social science alike - well-abled and adult men and women, who are presented as autonomous, self-responsible and independent persons. The independent individual is not only the standard of liberal political philosophy, it is its totem and its moral imperative. In seminal work, feminist political theorist Benhabib (1986) examines for instance how in the public sphere men are conceptualised as adults, alone, independent, and free from the ties of birth by women. She explores this metaphor in the works of Hobbes, Locke, Rawls, Kant and Kohlberg and argues that human interdependency, difference, and questions about private life are rendered insignificant to issues of politics and justice (see D5.1 by Anderson, Hartman and Knijn, 2017). Secondly, the dependency-independency binary is a historically dynamic construct instead of a universal concept. While independency once implied not having to work because of one's fortune or heritage (denying the dependence on and of numerous servants), the concept in the context of industrial capitalism is transformed into earning an 'independent' income as a wage worker (thus denying labour dependency) leaving all those who did not fit in that category as 'dependents' (Fraser and Gordon, 1994). Fraser and Gordon traced the negative connotations of the term dependency for non-wage workers in the rise of industrial capitalism:

*'what in pre-industrial society had been a normal and un-stigmatized condition became deviant and stigmatized (...) certain dependencies became shameful while others were deemed natural and proper' (1994: 315).*

Radical Protestantism promoted individual independence by way of wage labour, while paupers, natives and slaves, and also the housewife undergirded the 'independence' of the working man. Hence, 'dependent' became those who were not able or permitted to participate fully in the labour market: children, women, minorities, the old and the disabled. Thirdly, as Knijn and Kremer (1997) argue, no individual escapes being dependent once or several times during the life course. Every human being has been dependent on care in the first years of life, many will be dependent on care during lifetime and all will depend on care in the final years, unless one escapes via a 'sudden death'. Moreover, not only humans in their most fragile conditions depend on care, all humans do, all the time. It might be attention, emotional support, housekeeping either by the partner or paid housekeepers, by services offered by workers who take care for one's children or who serve one's elderly parents (cf. Ungerson, 1990; Waerness 1990; Ungerson and Yeandle, 2007; Le Bihan, Martin and Knijn, 2013). Fourthly, defining dependency has moral implications, not for pure reason (the ideal philosophical argument) but for practical reason (the non-ideal philosophical argument). The ideal philosophical argument does not say which ends we should choose, what is right (caring relations) and what is good (independency). In accordance with Kant's view however, in care relations the moral imperative is crucial in deciding whether conduct is "right," or moral, through empirical means, and what is right gets priority above what is good.

Evenly important for this paper is that it the ideal of care independency classifies and sublimates political hierarchies between various categories of people in need of care, those who can afford to privately pay for one's care - wealthy, well-earning men and women, the well-insured - , and those

who depend on public resources, charities, the community or family members due to low income, small pensions, severe chronic diseases or other constraints. The denial of human vulnerability and the idea of care independency in addition contributes to neglecting or underestimating the value of care work, in costs as well as appreciation (Folbre, 2006; Knijn, 2004). Therefore, as Knijn and Kremer (1997) argue, care is a matter of interdependency though it comes into practice in an unequal way' (ibid: 352). Taking the perspective of care as a matter of interdependency in which men and women, the old and the young, the able-bodied and the disabled are involved temporary or long-term allows for the recognition of care work during the life course for all humans. The next step then is to analyse the unequal redistribution of care that hierarchically constructs and produces inequality in the fulfilling of care needs and the division of care work.

Thus, analysing care work – unpaid in the familial sphere and underpaid on the labour market – and its systematic gendered distribution must start with the vulnerability of all, men and women alike. Recognizing interdependency here and now, or during the life course however does not suffice to overcome the gendered character of caregiving, also the stereotypical denial of men as caregivers must be taken into consideration. Recent sociological evidence (Hobson, 2002; Kramer and Thomson, 2002) shows a major and overwhelming trend of men, in all parts of the world, becoming aware, valuing and practicing care for all kind of reasons; practically because they live with an employed partner or a sick partner who suffers from Alzheimer, Dementia, MS or another nasty disease, emotionally because they like to share childcare and other family responsibilities, ideologically because they want to break through gendered boundary lines, and morally because they want to do the right thing (Hobson, 2002). Belonging has become a major intention in times of uncertainty and insecurity and many men, although not the majority and mostly not doing the lion share, have turned into caring personalities. In conclusion, 'care dependency' is an overall characteristic of humanity whether it concerns men or women, able-bodied and disabled people and the young and the old. Also, there is a reciprocal though unequal relationship between those who need care and those who give care. During the life-course people are interdependent, give and receive care on basis of reciprocal relationships and the moral obligations of care relations, although the latter by often means compulsory altruism (Land and Rose, 1985) resulting from gender, class and age-related power relations and hierarchies with consequences for redistributive and recognitive justice. The moral imperative at stake here is the relationship between the right and the good. Do care relations and its institutionalization contribute only to the good (the self-interest of the care receives and the care worker) or do they contribute to the right (their interdependent relationship)?

#### *Care, (inter)dependency, recognitive, redistributive and representative justice*

Are alternative formulations of care and dependency possible that may contribute to recognitive and redistributive justice, and if so, what do these imply for the boundary lines between the public and the private domain of care? A first consideration in line with disability studies is to argue that an impairment to a body does not necessarily constitute disability, which is only enacted through social construction in a social context and physically built environment (Ingstad and Reynolds Whyte 1995; Shakespeare 2000 in Anderson et al., 2017). In contrast impairment to the body for whatever reason – ageing, accident, genetics or illness - can be envisioned as normal part of human life. How this should be addressed depends on a combination of conditions and circumstances. For instance, McRuer (2006 in Anderson et al, 2017) criticizes the compulsory nature of able-bodiedness in contemporary western society resulting in the tendency to intervene in all kind of ways to restore

able-bodiedness. The main message of all kind of prevention and intervention strategies seems to focus on avoiding dependency for the reason of not becoming a burden to society and of not becoming a to be pitied person. Implicitly or explicitly being dependent on care is a stigmatized status which misrecognizes the normality of fragility and denies the person in need of care the right to construct one's own lifestyle. Following Sen's capability approach (Sen, 2005) one can argue that what goes for able-bodied persons also goes for elderly, chronically ill and disabled persons; the freedom to choose is imperative. This line of thinking is supported by Erasmus Prize winner 2018 Barbara Ehrenreich who in *Natural Causes* (2018) condemns self-help books aimed at older people by talking of "active ageing", "productive ageing", "anti-ageing", even "reverse-ageing". Such books promise a long life to everyone who makes an effort to workout, regardless of factors such as genetics or poverty. To Ehrenreich ageing is "an accumulation of disabilities", which no amount of physical activity or rigorous self-denial can prevent. Recognitive justice then would imply the acknowledgement that care needs are not a deviation to the natural state of being but an integrated aspect of human life, not a to be tabooed and stigmatized status that one can overcome by persistent acts of moving and training but a to be respected aspect of life. Therefore, recognitive justice is done if an impairment to the body is not seen as the equivalent of a disability taking away the control on one's life choices, critical thinking and dignity. By implication at an individual and societal level doing right to the identity of people in need of care, their preferences and choices is a condition for recognitive justice. To which has to be added that preferences and choices should not be taken by face value. As Anderson (2018, see D5.3) outlines, the debate on 'adapted preferences', expectations and preferences that are born in a given constitutional context, versus 'central human functional capabilities' is ongoing. Although hardly anyone can escape hegemonic paradigms such as those on 'active ageing' the critical reflection must weight these against its implications for the people who do not meet the criteria set.

What then are the implications for redistributive justice of care? Various approaches can follow from perceiving care needs due to physical impairments as a normal state of being. Whether one applies the utilitarian, the reciprocal, the consequential or the equality perspective, in all cases 'participatory parity' is conditional to redistributive justice (see D2.1 by Rippon et al, 2018). From a utilitarian or reciprocal perspective redistributive justice of care can be argued for because it is good for society to support people in need of care because leaving them behind without decent support negatively impacts on the good society. If only because the need can hit and hurt all members of society or their beloved ones at some unpredictable moment. Self-interest is an argument for supporting the care dependents. From a consequential perspective redistributive justice can be argued for in terms of altruism; bringing good to others is a moral social good contributing to the ethical quality of the individual and the society. However, this approach bears the risk of a hierarchical relation in which the do-gooder could be seen as morally superior while the user of care might be expected to be grateful. Morally based care giving might conflict with the recognition of (inter)dependency and the reciprocal relationship between care giver and care user. The equality perspective on redistributive justice of care does suppose this reciprocity by seeing that over the life time people give and receive care albeit not per se to the same degree. It recognizes the contribution care dependent people can offer to society and stimulates their 'participatory parity'. However, the risk of this approach is that it overestimates the capability of people currently in need of care to pay back and denies their incapability to participate on equal footing with the able-bodied. Compulsory strategies to bring them back in and a too great appeal on their autonomous functioning are the consequence of this

equality perspective. For redistributive justice of care, it follows that supporting people in need of care demands first social and societal support that contributes to the participatory parity of less-abled individuals. Which can take all kind of shapes and be offered in many ways, varying from wheel-chairs to home care, and from rehabilitation to residential care. Moreover, it demands respecting the dignity and free choice of care dependents for one form of support or another, not allowing a hierarchical relation between them as claimants and care institutions, insurance companies or care givers to whom they should be grateful. Finally, redistributive justice of care asks for facilities that on the one hand empower them in expressing their needs and realizing their choices without forcing them to be able to overcome their disability and its inconveniences. Compulsory programs to getting back to 'normal' in order to become less of a burden to society might seem right from a redistributive perspective but do not recognize the burdens of people in need of care.

Representative justice in the domain of care assumes that both care users and care givers have a say in articulating their needs and interests in the public arena. These needs and interests can be antagonistic in some respects such as the costs/payments or presence/working times. However, as Folbre (2006) says: 'Both producers and consumers of care share a common interest in quality of care'. Also: 'The quality of direct care work is difficult to monitor or to specify in an explicit contract. As a result, social norms and personal preferences have an important impact on the quality of care.' These social norms can be influenced by advocates representing the interests and needs of both involved parties. Advocacy groups of care users -elderly and disabled persons have organised themselves in the past decades at all governance levels, local, national, supranational and even global. In their turn they are well heard, financially supported and in some countries legally included in the care system, for instance in client councils and advisory boards. Professional care workers can be represented by trade unions and professional organisations who negotiate on wages, social protection and working times. Hardly represented are informal paid and unpaid care givers in the private sphere who only can express their voice in one to one deliberation with the one they care for or exit if the burden is too high. However, the latter option is limited for illegal migrant care workers due to their dependency on the job for gaining an income and staying in the country of destiny. Nevertheless, representation of care users and care workers in the public debate on care remains crucial because care services have an important public good component in improving human capabilities. Folbre (2006): 'The benefits of providing good care "spill over" to improve the well-being of the community as a whole.'

## SUMMING UP

In this first part of the paper the binary between dependency and independency is challenged from the perspective of care relations that instead are defined as interdependent, though unequal. The moral imperative of independency as a dominant discourse in liberal philosophy and political thinking obscures human nature and prioritizes the 'good' defined as self-interest above the 'right' of caring human relations. This affects cognitive justice for people in need of care and those who take care negatively by respectively the moral obligation to surpass their neediness and to show able-ness and the moral obligation to deny the value, intensity and time-consuming character of their work. It also has unjust redistributive effects on the participatory parity of both care receivers and care workers because a lack of resources and facilities. Finally, representative justice is damaged by the

moral imperative of independency precisely because voices of those assumed to be dependent, care receivers as well as marginalized care workers, are silenced.

## **PART II: EU discourse on private and public care for elderly and disabled individuals**

One of the objectives of this report is to map the various conceptualizations of care-related justice that arise in European Union on the care needs of older and/or disabled people. Such conceptualizations have relevance because they may influence public decision making in the Member States and at regional and local levels, even though they cannot prescribe such lower levels policies. The policy documents, guidelines, inspirational papers and many webpages on care for elderly and disabled people all belong to the category of 'soft law' and their implementation depends on national and lower level decision making. In addition to influencing care policies European level conceptualizations may affect the public and private narratives on care needs and how these should be fulfilled. The EU framing of care needs can open new horizons and alternative perspectives but also close, downgrade or devalue perspectives on care needs. By affecting the public opinion and attitudes on what care needs are and how these should be dealt with mind shifts can be realized. This is not to say, nor to exclude the reverse process in which EU thinking and policy development is inspired by bottom-up voices. Care users and patient movements have a strong lobby in the EU and have been rather successful in getting themselves heard. However, in the end it is the EU Commission, the Council and the Parliament that decide on what problems, issues and vocabularies will make up the final framework on care and on who and what is in- and excluded. Regarding care work the EU is more powerful because of the Social Charter (see ETHOS D6.3 and D6.4) and labour laws that belong to the 'hard law' of the internal market to prevent unequal competition and protect mobile EU workers. By implication care workers employed in regular jobs are protected, also the ones who work in another EU country than their own. This does not count however for many care workers who are employed privately by care users and for live-in migrants or care workers that work on cash-for-care schemes. They belong to the category of 'domestic workers' that are not included in EU regulation and are, with a few exceptions, not protected by national labour regulation. Here the public-private boundary is still very explicit.

### *EU policies for ageing and disabled populations*

In response to the demographic trend of an ageing European population due to low birth rates, the ageing of the post-war generation and longer life expectancy, the European demographic pyramid is turning upside down with fewer young and more older generations. In that context long-term care (LTC) for elderly and disabled people has become problematized in many Member States as well as at the level of the European Union; can younger generations continue to bear the costs of care for the older generations, should not the current pension age be extended now older people live longer and appear to be in good shape after retirement and what can older people do themselves to solve care dependency are some of the political issues debated that relate to intergenerational solidarity. These debates feed a new perspective on redistributive justice, not putting class or gender central but age and ability. Above (page 8-9) we have presented the European Commission's claim for expanding public expenditure in formal care services either by providing formal care services or by including care work in social protection systems (European Commission, 2013). That claims have been inspired

by the 'social investment approach' (Morel, Palier and Palme, 2012) which is one though not the only discourse operating at the level of the European union.

At the same time, and probably not coincidentally a recognition debate entered the political agenda phrased in the idioms of participation and independency of care users. Exemplary for these debates are two European initiatives; the European Disability Strategy 2010-2020 launched by the European Commission and the EU year of 'Active Ageing' promoted and celebrated in 2012. During 2012 all kind of activities are stimulated and/or subsidized with an ambiguous agenda, that is to turn the expected burden on the pension systems, the labour market and the care systems. In terms of the EU: 'Active ageing means helping people stay in charge of their own lives for as long as possible as they age and, where possible, to contribute to the economy and society.' (<https://ec.europa.eu/social/main.jsp?catId=1062>). EU policy measures existed in supporting Member States in extending working lives and related pension and social protection systems, developing guidelines to promote active ageing, an Active Ageing Index to assess the untapped potential of older people, a European Innovation Partnership for Active and Health Ageing to raise healthy life expectancy. Three priority domains were selected; Employment, Participation in Society and Independent living. For this paper the most care related issue 'Independent Living' is scrutinized, which' subthemes are: accessible and affordable transport, adapted houses and services, age-friendly environments, age-friendly goods and services, health promotion and preventive health care, and income security. Within the program the Social Protection Committee got the task to advise on adequate and sustainable long-term care by investing in preventative care, rehabilitation, age-friendly environments and care provisions that are better adjusted to people's needs and existing abilities (<https://ec.europa.eu/social/main.jsp?catId=1062>)

Regarding people with disabilities the European Commission has launched the European Disability Strategy 2010-2020, stating that:

*"The overall aim of this Strategy is to empower people with disabilities so that they can enjoy their full rights, and benefit fully from participating in society and in the European economy, notably through the Single market. Achieving this and ensuring effective implementation of the UN Convention across the EU calls for consistency. This Strategy identifies actions at EU level to supplement national ones, and it determines the mechanisms needed to implement the UN Convention at EU level, including inside the EU institutions. It also identifies the support needed for funding, research, awareness-raising, statistics and data collection."*

The Strategy pursues actions in eight priority areas: 1. Accessibility of goods and services for instance by promoting the market of assistive devices, 2. Participation in all benefits of EU citizenship such as in public life and leisure activities, for instance by quality community-based services, 3. Equality by combatting discrimination based on disability, 4. Employment by stimulating the labour market participation of persons with disabilities, also in the open labour market, 5. Education and training by promoting equal access to quality education and lifelong learning for disabled people, 6. Social protection by guaranteeing decent living conditions, combatting poverty and social exclusion, 7. Health by promoting equal access to health services and related facilities, 8. External action by promoting the rights of people with disabilities in the EU enlargement and international development programmes (<https://ec.europa.eu/social/main.jsp?catId=1137>)

In contrast to the 'Active Ageing' initiative the Disability Strategy is less care-oriented. Its main message is on empowering people with disabilities, to promote access to work, education and healthcare thereby offering support to fully participating in society on an equal basis with others. Interestingly, care for disabled people is hardly mentioned in this Strategy and if it is mentioned the intention seem to be that care should be prevented or at least not institutionalised. The Commission states that the intention is to

*'promote the transition from institutional to community-based care by using Structural Funds and the Rural Development Fund to support the development of community-based services and raising awareness of the situation of people with disabilities living in residential institutions, in particular children and elderly people.'* (p. 6).

In order to achieve that transition the EU will support national activities oriented at training human resources, adapting social infrastructure, developing personal assistance funding schemes. It will promote sound working conditions for professional care workers and support for families and informal carers.

The EU states that 'disability is a right issue and in line with the UN Convention on the Rights of Persons with Disabilities (UNCRPD), to which the EU is a party. (<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/the-convention-in-brief.html>). Indeed, both the EU and the UN focus on equal rights to participate in all domains of life, employment, education, health, the public domain and political representation. Or, in terms of the UN convention:

*'It takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. The main purpose is to turn the focus from people with disabilities from objects of intervention to active subjects who have the right to decide on how they want to live their lives.'* (<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>).

### *Active Ageing*

What kind of activities are initiated in the context of the EU's 2012 year of Active Ageing and what do these activities tell us about the boundary lines that are drawn between the public and the private domain and its effects on redistributive justice? The EU has set the agenda by giving an indication on what Member States might consider initiating, that is Independent Living. In other words, the EU is promoting de-institutionalization of long-term care and indicates conditions for that process, such as creating facilities for living outside institutions. The EU however has to leave initiatives to the Member States, sometimes it subsidizes initiatives but actually it cannot do much more than collecting what they see as 'best practices' at the Active Ageing website. This does not mean that the 'Active Ageing' agenda should be underestimated, setting the agenda already is a powerful mechanism in changing the idioms and thereby the hearts and minds of the public and all stakeholders in the care system. The Active Ageing agenda reinforces an already ongoing trend to de-institutionalization, it legitimizes that process by inviting stakeholders in all Member States to

present and share their Active Ageing initiatives. For this paper all 117 initiatives are examined in the domain of ‘Independent Living’ in which the five Member States belonging to ETHOS WP5 participate. That collection of initiatives represents European ideas on redistributive and recognitive justice related to care for elderly people.

Interesting is the different degrees of active involvement of ‘our’ five Member States (Tables 2 and 3). The UK is the most active participant in the Active Ageing program with 41 initiatives, Austria is an active participant too with 26 initiatives while the Netherlands (14 projects), Portugal (13 projects) and Hungary (12 projects) are modest participants. Although relevant, a few initiatives of the 117 initiatives are left aside specifically those oriented at income and budgets of elderly persons. These initiatives focus on intergenerational wealth transition and life-improving resources for the over 65s. Three initiatives actually did not focus on ‘Independent Living’ such as a national quality assessment of elderly homes initiative by the Austrian government (p. 29 of archive), an initiative aiming at energy reduction in elderly homes, and a Dutch private initiative to review the life and general atmosphere in care institutions (p. 30). Such initiatives seem to be less oriented on ‘independent living’. Hence, in total we have scrutinized 106 initiatives. Table 2 provides an overview of actors involved in projects developed in the context of the European Year of Active Ageing. A third of the initiatives are taken by NGO’s and about a third of the initiatives is funded by the European Union or the European Commission. Governmental participation mostly happens at the local and regional level, while national level participation is almost non-existent. Also, businesses are less active and if private corporations are involved they mainly participate in E-healthcare and ICT; robots, domotica, travel apps, etc.

Table 2: initiators/promoters of Active Ageing projects 2012

Country	Local/regional/ national	Research (Academic/ Professional)	Commercial	EU/EC funded	NGO	Total
Austria	6	4	1	10	5	26
Hungary	3	1	2	5	1	12
Netherlands			2	7	5	14
Portugal		5	3		5	13
UK	6	5	3	8	19	41
Total	15	15	11	30	35	106

Source: <http://ec.europa.eu/archives/ey2012/ey2012main2793.html>

Table 3 contains information on the kind of initiatives taken in the context of the theme ‘Independent Living’ of the year of ‘Active Ageing’. Here we see that only a few initiatives (about 10 per cent) directly facilitate social participation of elderly persons. Examples are free public transport, organising intergenerational meetings between elderly persons and secondary school students at which seniors help students to improve their communication skills, learn about history and teach the students to play old-fashioned games such as bowls and whist. Overall, promoting independent living

in the context of Active Ageing mainly exist in developing guidelines and tools (e-health apps and equipment), in workshops and meetings to distribute information and raise awareness, and in preventing care dependency. Such initiatives cover a wide range of issues of which stimulating physical activity is a crucial one. The assumption here is that older people insufficiently workout while exercising is crucial for healthy ageing. Exemplary for such initiatives is KIFLI (Keeping Fit in Later Life; <http://www.kifli.eu>) promoting increased activity among older people by offering people over 50 (sic!) a supporting framework with which to pursue physical fitness. It aims to:

*“Offering realistic ways for promoting physical activities for older people. Encouraging people over 50 to participate in physical activities. Developing effective online training material that can be easily integrated into everyday life. Developing common guidelines on training principles for older people. Providing trainers and facilitators with appropriate training resources.”* <http://ec.europa.eu/archives/ey2012/ey2012main2793.html>.

Digital tools also focus on the risk of getting lonely at older age, which indeed might be a consequence of the trend towards staying at home as long as possible. To prevent or reverse loneliness a market of digital tools is expanding such as a TV-based platform to advance the social interaction of elderly people, or a Windows Phone 7 smartphone:

*‘aiming at improving the quality and joy of their [elderly people’s] their home life, bridging distances and reinforcing social voluntariness and activation, thus preventing isolation and loneliness. facilitate communication mechanisms available to the elderly by redesigning the user interfaces of the basic functions of a Windows Phone 7 smartphone. It also includes the redesign of more advanced tools such as video calling and interconnection with social media in order to allow remote interaction with users of social networks, as well as synchronous or asynchronous conversation, covering also audio-visual communication.’* <http://ec.europa.eu/archives/ey2012/ey2012main2793.html>.

Quite a different approach to avoid loneliness is taken by a Dutch project called OPOEH that aims to match senior citizens who seek companionship and activity to families looking for a pet sitter. Many initiatives emphasize the risk of dementia preventing older persons to live an independent life in their private homes. Some of these initiatives aim to support volunteers and family members in their care for people suffering of mild and moderate dementia real-time assistance via mobile phone and geo-tracking technology when they suddenly suffer from orientation loss and feel insecure. This overview of activities organised at invitation and in the context of the EU 2012 year for Active Ageing shows a preference for everything but personalized care involving care work.

Table 3: Character of Active Ageing projects 2012

Country	Social participation facilities	Stimulating active lifestyle (guidelines, performance, workshops, etc.)	Empowerment/ Awareness (community building, abuse etc.)	Promoting Independent living (ICT, E-(health)care, information, etc.)	Total
Austria	2	4	7	13	26
Hungary	2	3	3	4	12
Netherlands	2	1	3	8	14
Portugal		2	6	5	13
UK	4	7	17	13	41
Total	10	17	36	43	106

Source: <http://ec.europa.eu/archives/ey2012/ey2012main2793.html>

The moral imperative is preventing passivity among elderly persons, their obligation is to become more physically and socially active in all possible ways. Being 'passive' at old age is tabooed because it is assumed to increase loneliness and most of all dependency on support and services, which should be avoided by all means. Awareness raising and information folders should serve the purpose of changing the mindset of elderly persons, their family members and the involved care workers. E-health equipment is a new niche in the market of elderly care providing all kind of tools to monitor one's own health, regulate medicine intake, communicate with community members or medical staff or guide physical training at home. The core ideological dilemma presented in this 'Independent Living' discourse is threefold; passivity versus activity, dependence versus independence and in the end institutionalisation versus de-institutionalisation. The latter follows from the argument that living in residential care equals doing nothing and being excluded from society and the community. Interestingly mainly NGO's, municipalities, organisations working for elderly people are initiative takers, few initiatives are brought forward by elderly persons themselves or organisations representing them. Also missing are 'rights' claims regarding redistribution of resources. The issue of cognitive justice is a complicated and complex aspect of the Active Ageing program. Is the recognition of elderly persons as persons who can still be active in society and should be encouraged to remain involved a matter of supporting them as dignified and valued members of society or is it a patronizing approach assuming that elderly persons are overwhelmingly passive consumers of care who cannot decide for themselves to live the life they prefer after a long working life? In applying Fraser's analysis of needs interpretations, it can be concluded that claims are mainly made by organisations that speak on behalf of elderly persons. The programs are phrased in terms of 'their own interests', a patronizing way of approaching elderly people of which it is not sure and even doubtful that it represents the feelings and experiences of elderly people themselves. Maybe some elderly persons might feel attracted to this new paradigm but even then, it is unsure if they feel represented by this idiom of Active Ageing that mainly offers guidelines, awareness raising and E-health equipment. More important is Fraser's second of needs interpretation, the modes of

subjectification. The discourses presented in the Independent Living part of the Active Ageing Year positions elderly persons – from the age of 50 on – as people to whom it is needed to address as specific sorts of subjects endowed with specific sorts of capacities for action. The ageing population in these programs are classified as passive, ignorant, isolated and not able to decide for themselves without intensive support to follow up the moral imperative of being active and to live independently. Interestingly they are pictured as victims more than as potential activists, and hardly any differentiation is made within the generation of elderly, they are approached not as unique individuals but as members of an age category.

### *European Disability Strategy*

Unlike the Active Ageing Year the Disability Strategy 2010-2020 did not collect a range of initiatives for promoting its aims. Instead it initiated some comparative studies on removing barriers for people with disabilities to participate in and get equal access to all domains of life (education, employment, health services leisure activities etc.) and to stimulate their human rights by combatting discrimination. Under the heading ‘Independent living & social services’ of the Disability Strategy the European Disability Forum (EDF) a Capabilities Approach is advocated stressing the inviolable and fundamental right of disabled people to choose and to make choices in life. In referring to Article 19 of the UN Convention on the rights of persons with disabilities EDF states that disabled people want to live independently in the community, to enjoy good quality services that will make possible for them, in the long run, to fully exercise their citizenship, their right to dignity and enable them to participate in society. <http://www.edf-feph.org/independent-living-social-services>

EDF is part of the European Expert Group on the Transition from Institutional to Community-based Care (EEG) <https://deinstitutionalisation.com/members/>, a broad coalition of about 15 NGO’s lobbying for de-institutionalization of care. Stakeholders are for instance UNICEF, people with mental and physical disabilities but also people needing care and their families and homeless people. Other stakeholders are service providers, public authorities and intergovernmental organisations. Among these is the European Association of Service providers for Persons with Disabilities (EASPD) in which about 15.000 service providers are gathered. EASPD speaks about a paradigm shift in society’s view on people with disabilities in referring to ratification by Member States and the conclusion by the European Union of the UN CRPD:

*‘This paradigm shift therefore requires a movement away from a medically oriented model of care, where the person with a disability is viewed as a passive receiver of care or worse as a person who needs to be cured, towards a social rights model where individuals are supported to become active citizens making a contribution to their own communities like everybody else.’*

[http://easpd.all2all.org/sites/default/files/sites/default/files/Policy/easpdroadmap\\_final.pdf](http://easpd.all2all.org/sites/default/files/sites/default/files/Policy/easpdroadmap_final.pdf) (p.1)

Like in the Active Ageing program a key counter-value (Billig et al. 1989) in the idiom of the Disability Strategy is ‘passivity’. The use of that concept however is not unambiguous. In the formulation above it is the medical model of care that saw people with disabilities so far as indolent, lethargic and to some degree lazy consumers of care waiting to be cured. In reaction one could expect that propositions would go in the direction of a revised medical model in which disabled people would

have a say on the care they receive, not aiming per se on being cured but as dignified, well-informed and capable people living with some impairment that does not undermine them in exercising their human rights. This is however only one part of a twofold paradigm shift. The other part is the shift towards community care in reaction to institutionalization; the transition from inadequate closed institutions to high quality community-based alternatives:

*'In the Common European guidelines on the transition from institutional to community-based care, the term 'community-based services', or 'community-based care', refers to the spectrum of services that enable individuals to live in the community. [.....]. It encompasses mainstream services, such as housing, healthcare, education, employment, culture and leisure, which should be accessible to everyone regardless of the nature of their impairment or the required level of support. It also refers to specialised services, such as personal assistance for persons with disabilities, respite care and others.'* (ibid: 3)

European Disability Forum is a main expert group on behalf of people with disabilities. The Forum promotes participation of disabled people in society as well as person-centred, quality and empowering models of services and formal and informal care that fully respect the human rights of all people with care or support needs. It also provides expert support on EU policy, legislation and funding. In 2016, EDF adopted the following definition of 'Independent Living':

*'Independent Living is the daily demonstration of human rights-based disability policies. Independent living is possible through the combination of various environmental and individual factors that allow persons with disabilities to have control over their own lives. This includes the opportunity to make real choices and decisions regarding where to live, with whom to live and how to live. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing persons with disabilities flexibility in our daily life. Independent living requires that the built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that Independent Living is for all persons with disabilities, regardless of the gender, age and the level of their support needs.'* (<http://www.edf-feph.org/independent-living-social-services>)

One way of realizing independent living is via individualised funding. In a large Campbell review of 73 studies on individualised funding for people with disabilities in Europe, the US, Canada and Australia Fleming et. al. (2019) found evidence for positive effects of this kind of redistribution. It appears to improve the quality of life, client satisfaction and safety though not physical functioning and unmet need. Nor is there evidence for cost effectiveness. Fleming et al (ibid: 6) state:

*'Recipients particularly value: flexibility, improved self-image and self-belief; more value for money; community integration; freedom to choose 'who supports you; 'social opportunities'; and needs-led support. Many people chose individualised funding due to previous negative experiences of traditional, segregated, group-orientated supports. Successful implementation is supported by strong, trusting and collaborative relationships in their support network with both paid and unpaid individuals. This facilitates processes such as information sourcing, staff recruitment, network building and support with administrative and management tasks. These relationships are strengthened by financial recognition for family and friends, appropriate*

*rates of pay, a shift in power from agencies to the individual or avoidance of paternalistic behaviour.'*

Recognitive justice for care users as well as care givers appears to be envisioned as a major benefit of individualized funding. Care users are recognized as autonomous decision makers making choices on what resources would best fit their needs. Care givers in their turn are recognized as supporters of the care recipients deserving fair payments for their efforts. The latter also refers to redistributive justice, care work is not for free and should be paid for appropriately. Interestingly, puzzling is the reference to power relations, the power shift from agencies to the individual in need of support is seen as a major advantage of individualised funds. A major barrier that care recipients complain about with respect to the individualised funds is the bureaucratic, arbitrary and unclear procedures for getting access to the funds, and the long delays in receiving them. Unarticulated in the mission of the EDF and unnoticed in the review by Fleming are the power relations between care recipients and care givers in the context of individualised funds; what are the implications for intimate and gendered relations if care givers' previous unpaid care work is commodified? Grootegoed, Knijn and Da Roit (2009: 19-20) conclude in a vignette study among family care givers receiving a care allowance (in Dutch; Persoonsgebonden Budget, PGB):

*'On the one hand, the care-givers regarded the payments for care as beneficial both to the carer and to the chronically-ill or disabled family member. Payments for care help to create a situation of balanced give-and-take, particularly in very demanding and intense long-term care relationships. In this way, the PGB compensates for onerous aspects of family obligations (Komter 2004). On the other hand, the introduction of an employment relationship between relatives alters care-givers' perceptions of their duties: the contract creates a stronger commitment and an increased duty to perform. The combination of the contractual relationship with affective bonds and moral obligations leads paid carers to make higher demands on themselves, not least by comparison with what is required of professional carers: they feel they should anticipate the care recipients' wishes and needs, provide better quality services and be reliable long term, even when there are competing demands on their time.'*

That delicate issue also remains unanswered in the Disability Strategy. In the chapter on gender equality the issue is only addressed from the perspective of the care user by formulating that female disabled persons should have equal rights as male disabled persons thereby denying the still gendered practice of care giving. Finally, more macro-level redistributive justice claims are addressed by the EDF regarding social services for persons with disabilities. Here EDF pleads for a restricted internal market for redistributive justice purpose:

*'An adequate internal market of services would allow persons with disabilities to benefit from quality services anywhere in the European Union, when travelling or living abroad. The EU should guarantee that these services are of quality throughout the EU; that they are not submitted to the same competition rules as commercial goods and services and that they remain accessible for all citizens.'* <http://www.edf-feph.org/independent-living-social-services>

More than the Active Ageing agenda the Disability Strategy is embedded in a human rights and capability approach. It incorporates the standpoint approach (see D5.1) in arguing against the medical model of disability popularising the social disability model according to which an impairment

to a body does not necessarily constitute disability. The Disability Strategy focuses mainly on adjusting the social context, transport, information, services and the physically built environment to the needs of disabled persons. 'In doing so they address notions of normalcy which construct deviant bodies that do not match bodily norms of set physical capabilities' (Davis 2017, in Anderson, Hartman and Knijn, 2017). Taking an additional perspective, the Campbell review (Fleming et al., 2019) more than EDF highlights a condition of Independent Living that is resources for personal care service. By evaluating individual funds, the perspective of recognitive and redistributive justice for care givers, which is almost absent in the EDF strategy, is taken into consideration. The absence of that perspective cannot easily be explained. Is it that the concept of care and the perspective of the care givers is infected by the association of care with dependency and thereby represents a moral obligation of viewing persons with disabilities as 'autonomous subjects'? In Fraser's terms the 'rights talk' dominates above the 'needs talk', but why so? One argument might be that one does not want to be seen as 'in need' but isn't this a denial of the care deficiency that is part of the post-modern care model as Hochschild (1995) pointed at? It appears that the denial of caring about, caring for and care work on the one hand contributes to the recognition of disabled persons to be autonomous and dignified persons but on the other hand bears the risk of giving way to redistributive policies that neglect their care needs as well as the needs and interests of the care givers supporting them. In one way or another, disabled persons have needs for support and care, need help depending on the kind and the degree of impairment. Denial of those care needs might contribute to the feeling of being autonomous but also to the neglect of interdependency. Why would it be important to deny such care work if it is delivered under the condition of the disabled person having a reasonable final say on how it is performed? What remains from these considerations is that with the denial of the concept of care in the EU initiative regarding Disability by articulating the rights of disabled persons in terms of autonomous participation another human right is at risk to disappear; namely the recognition of care dependency because one is disabled and in need of assistance, hence the right to receive care. From a recognitive justice perspective such care should be delivered in a non-patronizing way and the disabled person should decide on what kind of care, for what purpose and in what way it should be delivered. But the moral imperative of independency strengthens the neo-liberal idea that also this vulnerable category of the population has the moral obligation to compete with their fellow citizens on equal footing. Clearly some of the EU recommendations focus on social protection for disabled persons, such as those focusing on anti-poverty policies and equal access to health care. Though these might fall short if care needs are not recognized.

### **The mixture of public and private care in national policy practice**

In its working document on Long-term care in ageing societies, the European Commission (2013: 136) signals huge variations in public expenditure on long-term care (LTC). Long-term care expenditure as a share of the GDP is very low in Hungary, less than 0.5 per cent with lower levels found only in Portugal (and Estonia and Greece) among the OECD countries. The difference compared to the Netherlands (3,8 per cent) is especially striking. The Netherlands as a rich country is probably better able to cope with the costs of LTC but also has recognised the challenge of long-term care and developed a policy to deal with it (OECD/ European Commission, 2013). The public spending on LTC reflects the varying extent to which people with care needs receive formal services and differences in the use of home care and institutional care. The EC distinguishes five clusters of LTC provisions in which the countries in our study score as follows. The Netherlands is qualified as a country that has a

formal-care oriented provision, which is generous, accessible and affordable. Austria and the UK are qualified as countries offering a medium to low degree accessible formal care added up by a medium orientation on informal care. Hungary and Portugal cluster together as Member States with a low formal care accessibility and a strong informal care orientation (European Commission 2013: 13). In the following parts of the paper we focus mainly on residential care as the most public form of care for elderly and disabled persons.

As could be expected on basis of the conceptual analysis in this paper in none of the Member States a strict divide between public and private care exists. In residential care we see a variation between semi to full state-run residential homes as well as a mixture of for profit and non-profit residential care services supported by public means. Neither do countries strictly divide care services for disabled and elderly people. The argument might be that mentally sound but physically impaired elderly and younger physically disabled persons might need the same approach and service. Disability has no age criterium and therefore the strict boundary lines EU policy between 'active ageing' and the 'disability strategy' are at odds with care policies in Member States. This mixture of private and public domains and of support to disabled and elderly persons is also present in Portugal. In this country, care for elderly people, for people suffering from dementia and physically handicapped people can take many forms of which the oldest one still is related to charity-based organisations such as Santa Casa da Misericórdia, an organisation of private non-profit institutions of social solidarity committed to the practice of Christian charity. They offer all forms of intervention and social assistance for all kind of people in need of care, making them "frontier" institution between the church and the state (Brito, 2018). Such intermediate organisations of mainly Christian origin also have existed in the Netherlands during the entire 20th century but nowadays have developed into secular non-profit care providers. In addition, some for profit care providers entered the market (Knijn and Hiah, 2018), all of which combine care and support for disabled people no matter their age. In Austria residential care services for elderly and disabled people are provided by provinces and municipalities, or by religious and other non-profit organisations. These services usually include care in residential homes, nursing homes, day-care centres and night-care centres (Riedel and Kraus, 2010). In Hungary residential care for elderly is (still) provided by (local) authorities in nursing homes or hospitals with some additional provision by church-based NGO's, and here there the age criterion is fluid too.

Seemingly there is some confusion about how to cope with care for elderly and/or disabled people at the level of the EU with some stressing the advantages of formal services (EC, 2013) and others pushing for prevention, de-institutionalization and community care with the aim to live independently as long as possible. Are these antagonistic claims or can both perspectives go together? Given the ageing European population, the decreasing availability of female kin to give unpaid and informal care because of their employment and the fragmentation of local communities the question raises if de-institutionalisation can be justified and is doing right to the needs of elderly and disabled persons and care givers. But maybe in combination both strategies can go along under some favourable conditions accompanied with formal services facilitating independent living and new forms of institutionalisation that recognize people in need of care as autonomous persons living in care facilities. In combination such services adjusted to and respecting needs and interests of care users, might give them a free choice in their daily activities and help them to reach their limited capabilities. Combined with regulated, well-paid care work such an integrated care system might

offer both redistributive and recognitive justice to all involved. From the country reports it is evident that long waiting lists for residential care exist while at the same time de-institutionalisation of care services for elderly and disabled persons is the proclaimed but not (yet) realized strategy. Some of our countries effectively and intentionally have reduced the number of residential places but were not capable of implementing acceptable home care alternatives. Other countries expand the number of residential places despite their intention to de-institutionalize care services mainly because home care services are still in development. In both cases needs of elderly and disabled people are not recognized and unequal distribution among gender and class continues.

#### *Getting access, eligibility.*

Getting access to residential homes isn't an easy job, in some countries like the Netherlands it is a hard to take hurdle. During the past decades the country has closed almost all lighter forms of residence for elderly people, the elderly homes (*verzorgingshuizen*) where rather well-abled elderly lived together. Today only nursing homes for elderly offer residential care for the most fragile disabled and/or older people only after a strict assessment. At the same time services and facilities in these nursing homes have seen major improvements; people have an individual living-bed room and a private bathroom, the nursing homes have rather good quality restaurants, offer all kind of daily activities and physical therapy. They are run by qualified staff (nurses and qualified care workers) and many can count on an army of volunteers for indoor and outdoor activities. Two major problems remain: 1) a shortage of nurses and care workers and by consequence a high work pressure on all care workers, and 2) unacceptable waiting lists meaning that only 5 per cent of the nursing homes can take in a person in need of high-level care within the legally set period of six weeks, almost 50 per cent of the nursing homes indicate in 2017 that they cannot guarantee to accept a new resident, maybe even not within six months (<https://www.actiz.nl/nieuws/ouderenzorg/2017/08/onderzoek-wachttijden-verpleeghuizen>).

The shortage of care givers interestingly is the result of austerity policies of the Dutch government during the crisis in combination with the highly regulated labour market for registered health care professionals (regulated by the *Wet op de Beroepen in de Individuele Gezondheidszorg*, BIG). Many nurses lost their jobs in 2013-2014 because of government cutbacks and consequently lost their BIG-registration as a qualified nurse because they had an insufficient number of working hours. In order to regain their registration, they have to re-educate and take new exams, which discourages many potential candidates (UWV, 2017).

Hence, while in recent years a decreasing number of people have become eligible for residential long-term care the waiting lists did not reduce. In particular people with physical disability and psychiatric condition (not meaning mental disability) are less eligible for residential care as a result of the 2015 long-term care reform (Statistics Netherlands, 2017). In 2015 about 117,000 older and/or disabled persons lived in a nursery home, mainly women above the age of 80 (average age is 87) most of whom are widows. Access criteria for these nursing homes are very strict because various thresholds and barriers. In general, a person will be assessed for residential care (via *Wlz-zorg*, see Knijn and Hiah, 2018) because of a somatic, psychogeriatric, physical or sense impairment requiring continuous supervision, nursing or support as well as 24/7 care availability (tk 2013/2014: p. 3). Because of these strict access criteria all people living in nursery homes experience limitations in daily life due to health problems. They have problems with housekeeping, personal hygiene, mobility

or are unable to help themselves at all. About a third of the inhabitants sits in a wheelchair, about 75 per cent has memory problems, and about 80 per cent has serious physical impairments (Verbeek-Oudijk and van Campen, 2017).

Like in the Netherlands also Austria aims to reduce residential care by expanding budgets and facilities for care at home. National guidelines for residential services are lacking because of the decentralised care system. For instance, Scholta (2008 in Riedel and Kraus, 2010) shows that some provinces require 100 per cent of all places to be in single rooms, other set much lower criteria and even allow for triple or 4-bed rooms. In Austria roughly 80 per cent of all elderly persons in need of care are receiving informal care (Badelt et al., 1997; Nemeth and Pochobradsky, 2004; Hörl, 2008 in Meier, 2018) in most cases care is provided by family members, mostly women. While people in need of care are entitled to receive a care allowance, they don't have an entitlement to a place in a nursing home or to receive formal care at home. Meier (2018: 5) reports that for people with disabilities a national action plan is launched stating that "in the area of housing a wide-ranging programme of de-institutionalisation in all provinces is necessary." Large institutions must be reduced and aid for persons with high care needs has to be installed to facilitate their independent living. In contrast to the Netherlands access criteria for nursery homes are less rigid but the decision to accept a new resident can arbitrarily be made by the nursery home administration. There is no entitlement to be allocated a place in a nursing home or to receive formal care at home nor is there is a special assessment procedure in the course of entry into a residential or nursing home. Actually, a residential home is free to accept or reject applicants. In cases of more demand than the supply of places, nursing homes usually require a certain level of care needs, for which the threshold is that a person at least needs more than 120 hours of care per month (level 3). The needs assessment then is based on an expert opinion by a doctor or a nurse who do an examination in the home. (Riedel and Kraus, 2010). Since national regulation is non-existent, the quality of services is not defined leaving room for considerable differences in interpretation implying that no right claims can be made by people in need of care.

While almost all countries in this study intend to restrict access to residential care in practice this appears to be a hard to implement intention. Despite a lot of efforts to substitute residential care by care in the private home waiting lists for residential care are increasing in Austria, the Netherlands and Portugal alike. In Portugal long waiting lists persist, particularly for the low-cost, non-profit institutions where families pay according to their means (Joëlle, Dufour-Kippelen and Samitca, 2010). The country is expanding its residential care services because of long waiting lists for vacant places in nursery and elderly homes. Nevertheless, there is still a shortage of places. Brito (2018) explains this by the growing number of people who cannot live alone, many of whom have opted for living in residential care homes. So, and despite the introduction of the concept of healthy and active ageing and the assumption in the "Handbook of key-processes to the Residential Structure for the Elderly (RSE)" (ISS, 2014) of "the possibility of the person remaining autonomous and able to take care of him/herself in his/her natural environment", residential care constitutes a "social response intended for collective housing, in a context of assisted living", for persons of the same age as established for retirement,

*'for persons at risks of losing independency and/or autonomy, that by their own option or because of a lack of social background, and without dependencies caused by an aggravate state of health that would require the need for continued or intensive medical care, intend to*

*integrate into a residential structure, being able to access biopsychosocial support services, oriented to the promotion of the quality of life and to the conduction of a healthy aging, in an autonomous, active and fully integrated way.'* (As cited in Brito, 2018: 12)

Here an alternative perspective on residential care is presented that integrates the assumptions of autonomy, participation and quality of life. It does not aim for community care as the only option for human dignity of people in need of care but requires a redefinition of what residential care could mean under the condition of recognitive justice.

*'Thus, the objectives of the RSE (Ordinance nº67/2012) are to provide permanent and adequate services to the biopsychosocial problems of the elderly; to contribute to stimulate an active aging process; and to create conditions that allow preserving and encouraging the intra-family relationship and social integration. The principles of action are the maintenance of quality of life, life efficiency, humanization and respect for individuality; full assessment of the resident's needs; the promotion and maintenance of functionality and autonomy; the participation and co-responsibility of the resident or legal representative or family members. These principles are used in the preparation of the individual care plan.'* (Brito, 2018: 12).

Access criteria (Article 5 of the Ordinance, RSE) are less strict than in the Netherlands and more clearly articulated than in Austria. Eligible are persons over 65 years old, who cannot remain in their homes due to familiar reasons, dependency, isolation, loneliness or insecurity. The residential setting can also offer accommodation in case the informal caregiver is absent, impediment or in need for rest. Like in the Netherlands the residential homes offer adequate alimentation, personal hygiene care, laundry service, room cleaning, daily and communal activities, stimulation and maintenance of physical and psychic capacities, nursing and health care and administration of medication. Brito (2018: 12) adds that it 'is expected that the structures should allow social coexistence, the relationship between the residents and those with the family and friends, the caregivers and the community itself.'

Residential care services in Hungary are of much poorer quality than in the countries evaluated above, and individualized care is far from available. Elderly care in Hungary builds on long-lasting residential care and despite a tendency to strengthen home care most formal elderly care still happens in large institutions or as residential care away from the home of the frail elderly in which for instance no doctors are available (Veres, 2018). The description of the residential homes in Hungary indeed resembles the 'cold-modern' care model, Hochschild (1990) pictures. According to Czibere and Gál (2010) these residential care centres serve meals three times a day, give clothes (if needed), and provide mental and physical health care. However, in 2010, 75 per cent of the rooms serve three or more clients and have no separate bathroom, and not much has changed since then. Nevertheless, and in spite of an increase in the number of beds in residential homes since 1990, there are long waiting lists for residential nursing care services (to be distinguished from long-term health care in hospitals) as a consequence of the inadequate operation of the home help and home nursing services and the poor state of older persons' health. Only five per cent of people over 60 years live in homes and the new non-profit and for-profit institutions have only slightly reduced the gap between supply and demand (Veres, 2018). Whereas over half the elderly has a certain level of dependence, some eight per cent has access to formal care. Even in the 80+ cohorts the access to residential care of individuals living with severe dependence is limited to a minority. The rate is

higher among women than among men, in particular above the age of 70, because women are more likely than men to remain alone. In general, more than 80 per cent of the dependent elderly do not have access to home care, and about 60 per cent of severely dependent persons do not have access to residential care (Czibere and Gál, 2010). Veres (2018) states that the situation became worse since in 2008 the threshold for mandatory residential home provision was even raised to towns from 10,000 to 30,000 inhabitants and the conditions for admission to a residential home were modified in such a way that only persons requiring over 4 hours of care a day were eligible. Assessment of needs is initiated by a doctor and carried out by an expert committee using a complex system including independence in daily activities, self-reliance, walking, mental functions, eyesight and hearing, the need for health and supervision, social circumstances, and financial background. These access criteria are more generous, or less strict as one likes, than in the other countries in this study probably because of the absence of sufficient home care services. However, they mainly result in long waiting lists. By consequence, those who do not get access to residential care are forced to turn to relatives or neighbours. Most of the care provided for elderly persons is informal in Hungary and in Turkey as well. The latter country does not see care as a public responsibility. The exception is if the family loses its capacity to provide care for a dependent person or if a dependent person has no a family or a relative to take care. In that case the state replaces the family and assumes the role of care provider. Care services that address the general public have never been institutionalized (Akkan and Simer, 2018).

### *Affordability*

Does the intended but not everywhere practiced trend towards de-institutionalization also imply that costs of residential care have increased, and if so, have extra financial barriers been implemented to discourage people in need of care to move into a residence?

In the Netherlands elderly homes and nursing homes have been subsidized by the government, mandatory health insurance added up by income related contributions of the care user till 2015. Since then the costs of living-in and care have been split in such a way that the residents pay for the housing accommodation themselves while the care services are paid for by the government and the health insurance (WLZ). In total about 15 per cent of the national health budget is reserved for residential care for elderly and/or disabled persons. The costs for residents are still income related having the effect that it is much costlier for high income residents who by consequence tend to move away to elderly or nursing homes offered by the private market.

Costs are part of the barrier for access to the Portuguese residential care homes. Recipients do contribute in the costs and are supported by the state taking political responsibility for social protection and the coverage of health care provision by the Ministry of Health. The State cooperates with the Private Institutions for Social Solidarity (*Instituições Particulares de Solidariedade Social*, (IPSS), to regulate care services and to secure a significant part of the financing. Additionally, Portugal has introduced several care allowances for pensioners who cannot live at home without being supported by care givers. Still, it is only a small sum, which does not represent a 'salary' for the carer (Joël, Dufour-Kippelen and Samitca, 2010). It has to be concluded that on the one hand access to residential care is limited because of the long waiting lists for non-profit institutions for which the costs are covered by public funds and because most people in need of this kind of care cannot afford the required co-payments for marketized residential care. On the other hand, the additional financial

support for home care falls short because of low budgets. By consequence there is skewed access to residential care with limited access for low income families to poorer quality care service. Only for some high-income families in need of care residential care seems to offer an appreciated alternative for care at home. This is well-illustrated in the Portuguese country report that pictures a family living in the 'New Wing' of a residential home, which in contrast to the 'Old Wing' offers more privacy plus service on demand (Brito, 2018):

*'Susana is 74 years old and Paulo is 77 years old. They had lived for a long time in Luxembourg as migrants, having returned to Portugal upon their retirement. They have a house in town but since they don't have children and their formal caregiver decided to emigrate, they opted to go to live in the nursing home. In the institution, elders are left alone in various moment of the day. Most of the care users are in wheelchairs, so they are immobilized when they are alone. Those who can walk, as with this couple, can be physically safe. The building, a former hospital, was adapted to minimize accidents. Access to the ground and first floors is through access ramps. To go to the second floor there is a lift used by both staff and care users. This floor is also served by stairs. All bedrooms have an emergency bell that the care user can activate in case of necessity, both night and day. Susana and Paulo need some assistance to get in and out of bed. Susana wears diapers and also needs assistance with washing. Besides that, although with some difficulty, they could eat and move about the house as they wish. They were certainly the care users who moved most freely in the institution, meaning they both enjoyed more freedom but also were often left alone since they didn't need so much assistance. They also were perfectly able to verbally communicate with ease. The costs of their institutionalization were fully funded by them.'*

However, also in this more privileged setting deficiencies seem to be unavoidable. Despite their own decision to go living in the nursing home Paulo feels that the situation is not optimal. He longs for more attention and freedom to choose how to spend their days (Brito, 2018: 44-45).

*'Sometimes we would like to go and take a walk in the city, but nobody can go with us. We are stuck here all day long, going down to eat, going up to watch television, going down to eat again and going up to sleep. Every day is like this.'*

Susana adds:

*'(...) for me worst is after lunch, when we are alone in the little living room. It's rare that someone goes there too... We can walk so we go anywhere we want. Sometimes we take a nap, but sometimes I don't want to sleep, so I stay here. Those who are in wheelchair can't go where they want, and 'the girls' don't take them here, so we are alone most of the time.'*

Recently, Austria has implemented a major reform in the financial contribution of family members for residential. That reform indicates the complexity of shifting boundary lines between the public and the private responsibility for residential care. On June 29, 2017 the Austrian National Assembly has abolished a regulation called 'Regress' meaning that the state must not any longer access money for residential care from the care receiver's relatives. In addition, since January 2018 the state is also not allowed anymore to recourse to the property of care receivers in residential care, the property of their relatives, heirs or donees. Social Security Act (BGBl. I Nr. 125/2017, in Meier, 2018). Till then institutional path-dependence within the familialist Austrian welfare regime made family members

(partners, children, grandchildren) to step in for the costs of residential care if the care recipients' income does not suffice. Care recipients themselves had to finance the cost of the residential or nursing home but if that income (pension and care allowance) and assets did not suffice, the respective provider of social assistance had to step in to cover the difference. This was often the case because the costs of residential care outweigh the average pension income plus a care allowance (both tax-financed) to a large extent, more so if care needs are more severe (Riedel and Kraus, 2010). In that case, according to Riedel and Kraus (2010), the care recipient usually keeps 20 per cent of the pension income and a smaller share of the care allowance as 'pocket money' for instance for pedicures, medicine, etc. 'Regress' was applied by provinces to a varying degree, e.g. with regard to the question of which relatives can be approached – spouses, children or grandchildren. Interestingly, while there is no direct evidence of a relationship between this familial responsibility and the reluctance of Austrian care recipients to move into residential care, a striking fact is that since provinces can only approach spouses for Regress the demand for nursing homes places immediately increased with about 15 per cent (Meier, 2018). These reforms indicate a major transition from private to public responsibility for the costs of residential care, hence a shift in boundary lines between the two care domains. In other words, the Austrian intention to familiarize and de-institutionalize care to an even larger degree than already was the case, might be blocked now the financial assets of kin are not any longer a stake if one opts for residential care. The process towards Independent Living appears to be a human right embedded in and fluctuating with the context of familial financial interdependency.

The Hungarian residential care is unable to cover all demands for care people in need of long-term care express. In that respect it does not deviate from the other three countries in this report. What makes it exceptional is its poor and obsolete quality that the Hungarian government was unable to improve till today. Veres (2018: 19) indicates that 5 per cent of people over 60 years live in homes that in some cases are paid for from the health care budget, in others from the social welfare budget. Czibere and Gál (2010) add that local authorities may charge user fees. The exact amount varies from service to service, taking the user's personal income and real estate assets into account. In 2010 according to Czibere and Gál the maximum fee is 80 per cent of the monthly income for residential care, 60 per cent for provisional residential care and 50 per cent for rehabilitative respite care. There is a difference in the amount of user fees in the governmental and in the non-governmental sector. Veres (2018) states that additional charges for extra services important for the elderly (such as physiotherapy) and other costs (e.g. medicines) sum up to a total monthly fee to be paid for nursing that is equivalent to or more than the average wage. That also private care services are underdeveloped is because of the small (strata-specific) size of the target group: only the upper middle and middle class and people with savings can afford these services. According to Veres (2018) members of the middle class are able to use of market services for a short period, but over the long term such services consume their savings. Hence, it is partially the costs that withhold elderly or disabled persons to live in residential care, and partially the poor quality tempering the demand for a place in such as setting. The main threshold however appears to be the low level of access to all kind of LTC services due to limited public resources available. Czibere and Gál (2010) and Veres (2018) also point to the lack of cooperation and coordination with alternative providers and between social care and health care in legislation, funding and provision. Moreover, fragmentation, decentralisation to local authorities and austerity policies during the economic crisis still stand in the way of sufficient and good quality care services and adequate care allowances. As said in Turkey, the state provides

care allowances for the family member to provide care to the disabled in the family. The state supports care services only for dependent persons whose family cannot take responsibility due to lack of resources or because there is no relative (anymore). The country recently has enacted in 2006 the option for private entities to open up rehabilitation and care centres. For these services the state pays a monthly amount equal to a double minimum income for the care of the beneficiary disabled. That amount covers the whole costs and, in its turn, is received from the care user on a basis of a means tested benefit, based on the family income and disability level (gravely disabled). Those who do not receive such a (conditional) subsidy could get these services by out of pocket payment. The number of private rehabilitation and care centres has increased from 10 in 2007 to 231 in 2018 (Akkan and Serim, 2018).

### *Living and working in residential care*

What does working in a residential setting imply for care workers and in what way does this reflects care users' perception? There is little evidence for answering that question in the D5.3 ethnographies because only one case is situated in that setting. Nevertheless, the D5.3 reports contain information on the qualifications required for working in a residential setting, work conditions and payments, each an important indicator for redistributive and recognitive justice from the care workers' perspective. Another aspect is the way the turn towards independent living affects also care workers' perception of residential care. An interesting case in this regard is the way Dutch home care workers think about residential care. When asked about how she feels about working in a residential setting Barbara, a Dutch district nurse associates this with working in a hospital:

*'It is a very different way of providing care. The clients are your guests, and they have to keep to the rules of the hospital. [with home care] you visit your clients at home, in their own environment [...] I have to stick to their rules and how they want me to care for them [...] that's a whole different way of providing care. And also [clients] prefer to be at home rather than in the hospital, so therefore the atmosphere is different [...]' (Interview with Barbara, district nurse)*

Her colleague Selma assumes the hospital regime to be dominant in nursing homes too:

*'If you look at nursing homes, people become in a matter of time accustomed to the daily rhythm. At 7 o'clock they are woken up to take their medicine. They get breakfast at 8 o'clock. At 12 o'clock they get hot food. They get a sandwich at 5 o'clock. At 11 they are helped to the toilet. At 3 o'clock they get to go to the toilet one more time. In the course of time you will notice that as soon as something deviates from this rhythm, they will become completely unbalanced. Completely disrupted. They also cling to each other a lot, 'You have me, you belong to me'. And that is much and much less the case in at home situations.'* (Interview with Selma, personal healthcare auxiliary)

These care workers consider home care as more personal in terms of relationships between care providers and care recipients; recipients have more agency, because they are still fit to live by themselves, and they are functioning in their own environment according to their own rules. Interestingly they consider all institutional settings such as the hospital and nursing homes to be equal in delivering impersonal care. According to them clients have less agency and must stick to the institutional rules. However, an evaluation study in the Netherlands shows a more positive picture:

*'Residents generally take a positive view of the care they receive, though frequently feel that staff have too little time for them and that the care is rushed. Residents more often felt they were taken seriously in 2008 than in 2004. Residents who need help using the toilet also more often receive help when they need it (rather than at set times). However, residents were less positive in 2008 than in 2004 regarding the amount of time that staff have for discussing life questions.'* (SCP, 2011)

Indeed, it is mainly work pressure due to the reduction of residential place in elderly homes in the past decades (between 1980 and 2010 the numbers have reduced from about 150,000 to 84,000 (VNG, 2014), the increase in elderly home places (from 46,000 to 74,000 in the same period) and more importantly the much stricter eligibility criteria. Hence, the care users living in nursery homes are much more care dependent, they need more personal hygiene, physical support and mental guidance. These same processes have increased working pressure for care workers who have less time for personal attention in Dutch nursing homes. The increase in the average severity of care is one consequence of elderly staying at home as long as possible. Therefore, it is not surprising that the Inspection reported on quality problems in nursing homes in the first decade of the 2000s (IGZ, 2004) that has stimulated attempts to formulate standards for good long-term care, and then subsequently to comply with those standards. But also the quality of entrants on the home-care market showed serious quality problems (IGZ, 2009). Complaints are presented on the expertise of the staff, shortcomings in medication policy, guidelines and standards for nursing were unknown and were not used and records were not kept systematically (Mot, 2010: 37). At the same time these researchers conclude that:

*'The notion of what is an acceptable quality level for the elderly and the handicapped has evolved over the years. The required quality level has risen – for example, as regards single person rooms in nursing homes. In a completely egalitarian system, all quality improvements should be available for all users under public insurance. However, this would make the system rather expensive. Another approach would be to define a certain level of quality for the public insurance system and to have higher quality care be funded privately. While the system in the Netherlands is not completely egalitarian, it is not too far from it. Most of the quality improvements of the last ten years have become available for everybody, rich or poor.'* (ibid: 43)

More and more, only the more severe cases end up in an institution. The case study in the Portuguese nursing home confirms that indeed agency of residential care users is rather limited. Brito (2018: 39) indicates that lack of time to provide care is an issue frequently mentioned by the care workers. Helena, care worker describes the work in the early morning as follows:

*'[F]irst, we need to wake them up, although most of the times they are already awake. After that I go grab water and towels. The caregivers from the previous shift leave the clothes for us to dress them. Then we undress them, we wash their face, hands and upper body. After that we take out their diaper, wash their lower body and put a new diaper. If they have it, we pass some cream on their body and then we dress them. In the end, we sit them on a wheel chair if needed, if not, they wait in a normal chair in the hallway.'*

This waiting can last for hours because some care users are up since 7h30 and must wait until past 9h30 to go eat breakfast. If in the meanwhile a care user has to use the toilet the care worker appears to have no time to assist her, resulting in the following discussion:

*'Helena: Mrs. Susana, I can't take you to the bathroom! Susana (care user): But I want to go...do you know what is like to use a diaper? It's not easy! Helena: oh dear, I know, but we don't to leave you here alone, I cannot be only with you. I need to go helping the others.'*

Having to use a diaper because of her incontinence is a humiliating experience for Susana. She explains that she would like to be able to use the bathroom when she wants and not to be dependent upon the help of the caregiver. Brito (2018) explains that issues surrounding hygiene are the most common among the care users, who would prefer to be able to take care of their hygiene alone but are dependent on the availability of the caregivers or constraint by the routines of the institutions. The care worker indicates that their lack of time for paying attention to care users' personal needs is due to two parallel restrictions; more severe and dependent care users and not enough staff to support them. Helena: "I have been working here for the last 5 years. I wish I could tell you that it's getting better each year, but it's not". She says that some of her colleagues who worked in the institutions since the beginning have told her that when the nursing house opened most of the care users were fully independent, only some of them needed fully physical assistance. Now is the other way around, meaning that the care worker spends most of their time providing physical care and little emotional care (Brito, 2018: 41).

What implications these processes have for the required qualifications care workers in residential homes, their wages and working conditions? Recalling the social investment approach of the Long-term Care evaluation of the European Commission a bright horizon is opening up in its presentation of public sector care containing LTC (home help, home care and nursing homes) financed from general tax revenue, organised as a public service and delivered by trained public sector workers to those who need care as an individual right. The European Commission (2013: 15) states:

*'Key advantages include: a solid financing base with full pooling of LTC risks across the population; maintenance of a larger formal workforce contributing to GDP; jobs with upgrading opportunities for lower-skilled workers; well-trained professional carers; and alleviation of the burden on families, so that people with dependent elderly relatives can continue full-time employment. The rights of those needing care are far better protected. Quality can be fully monitored and there are opportunities for growth in productivity, including through re-engineering and capital substitution. Taking care into the formal sector unlocks it from the constraints of families and makes the cost of delivering long-term care far more visible and amenable to public policies.'*

Whether a well-trained professional care labour market offering well-paid jobs to low-skilled and high-skilled workers alike is in place depends on the way Member States regulate this niche of the labour market. In Hungary this is dubious. Veres (2018: 20-21) concludes that 'The firms providing eldercare on the legal market charge high prices because of the high wage-related costs including social insurance contributions, as well as maintenance costs and concerns regarding their profit margins, while the carer they employ receives a very low wage, often less than half of the fee, further reduced by income tax.' The Turkish Ministry of Social Policy and Family arranging working

principles of the private nursing homes and elderly care homes, uses a very broad definition of elderly care worker (Akkan and Serim, 2018). Elderly care workers graduated from a vocational school, a university in the area of care or graduated at least from a primary school and has attended the certificate programs of the Ministry of Education and received a certificate.

*'According to the Article 18 of the regulation, the tasks and warrants of the elderly care staff are identified as: Physical care of the elderly, if needed assist the elderly to eat his/her meal; assist the elderly to organize his/her room, keep the room tidy; assist the elderly in meeting his/her physical and social needs.'* (Akkan and Serim, 2018).

Despite this recent regulation elderly care in Turkey is similar to Hungary channelled into an unprotected the black market for low-skilled and mainly migrant women due to the reasons presented above; shortage of places in residential care, high costs for private residential care service that go along with a low-costs, unregulated and highly flexible home care market.

The residential care labour markets in Austria, the Netherlands and Portugal are quite different from these in Hungary and Turkey. Despite a lower in GDP in Portugal compared to the two other countries, the country has established well-regulated labour conditions for its nursing home workers that are compatible to those in the Netherlands. Via Collective Labour Agreements (CAO 2018-2019, Brito, 2018) the rights of care workers as employees are legally regulated with regard to working weeks, resting periods, remuneration of extra work, night work, salaries, holidays, social benefits, professional updating and training, information, etc. In both countries also obligations of care workers are described. The Portuguese guidelines include obligations like complying with professional guidelines, ethics and secrecy, respecting dignity of the care users, colleagues and other stakeholders, providing the best service, humanized and individualized, ensuring the conservation and good use of available resources complying with hygiene and safety standards at work, favouring the efficiency and proper functioning of the services provided by the nursing home, maintaining and permanently improving professional competence, and refusing any gratuity, from the care user or their informal caregivers.

Residential elderly care is performed by – mainly women – with various degrees of qualification, ranging from low-skilled care assistants to high qualified nurses. An evaluation study shows that five percent of the residential care workers has the highest degree of Hbo nurse, 12 percent is qualified at the middle vocational nurse level, 42 per cent at the lower vocational care level and 8 per cent is care assistant. (Korte, de, no year). For all paid care workers hourly wages differ by level of needs and the qualification of the care worker, contracts are made up by care provider offering in kind service. Medium and high-level care workers' qualifications are protected by Article 34 of the Individual Health Care Professions Act (*Wet op de Beroepen in de Individuele Gezondheidszorg*, BIG). This concerns nurses (Article 3 of the BIG Act) and care assistants in individual health care (*Algemene Maatregel van Bestuur*, AMvB). If a care assistant does not work alone, a level 1 or 2 (vocational) training programme suffices. Nurses in the Netherlands generally complete a four-year training program in higher professional education (Hbo). The lower skilled workers in the Netherlands are protected by the Collective Labour Agreement in case they have a formal labour contract. However, (Korte, de, ny) many care workers in nursing and elderly homes work part-time; about 21 per cent works less than 20 hours per week and about a third works 20- 28 hours per week. Shortage of care workers could be reduced if care workers would accept more working hours per week. Alarming is

that about half of the care workers in residential care experiences a too high work pressure probably one of the causes of high sickness absence (Korte, de, no year). Like in Portugal residential care workers in the Netherlands indicate that they lack time to take care for and give attention to the residents.

## **CONCLUSION; A CHAIN MODEL OF CARE.**

Many elderly persons are well capable of living an independent life as are many people living with a physical impairment. Generalisations and categorisations of 'the elderly' or 'the disabled' do not justice to the rich variety of capabilities, lifestyles and able-bodiedness within and among both groups of people. Physical impairments cross age categories and should be strictly distinguished from mental impairments that limit individuals to make their own decisions. From the perspective of recognitive justice it therefore is imperative to not classify elderly and disabled persons as vulnerable categories of the population per se and to avoid a patronizing approach that neglects their freedom of choice to live the life they prefer.

Nonetheless, substantial parts of the elderly population are vulnerable because of bad health, poverty, loneliness or a combination of those problems. Also, many people with physical impairments cannot do without societal support and care; they might need healthcare, resources for care-related costs, access to work, income and transport for living their daily lives in a dignified and preferred way. From a redistributive justice perspective, it therefore is imperative that social care and support is available for those elderly and disabled persons who lack the means and resources to participate on equal footing in society.

The care and support for the vulnerable groups of elderly and disabled people is a major social worry in rich and weak welfare states alike because of demographic reasons, ageing populations, increasing costs of healthcare, transformations in the gender relations, and recently the economic and financial crises. Welfare states' options to address these problems differ extremely in relation to their GDP, their historical legacy and institutional path-dependency. Also welfare states' cultural and moral values, and their family and gender ideology influence how needs and interests of these vulnerable groups are dealt with. A complicated factor is balancing the interests of the old and the young; too much resources spend on the elderly may go at the costs of investments in the younger generation.

In that context a search for redistributive and recognitive justice has inspired the European Union, the European Commission and the Parliament to develop various alternative scenarios for how to cope with long-term care (LTC) for the ageing population and what strategy would accommodate best the needs of disabled persons. In this paper we have evaluated these initiatives and concluded that two alternatives are presented at the European level. One initiative founded on the 'social investment approach' favours formal care services by supporting, subsidizing and regulating care allowances or residential care. The other initiatives, 'Active Ageing' and the 'Disability Strategy' both favour de-institutionalization by way of prevention, E-health and community care. At first sight these alternatives represent contradictive even antagonistic interpretations of the needs of vulnerable elderly and disabled persons and different discourses of their interests. The needs of care users in the social investment approach are articulated in terms of quality control, risk-pooling and protection of care users' rights. Care policy options proposed are either residential care facilities or publicly financed and state-regulated paid care at home. In the alternative scenarios the needs of care users

are phrased in terms of autonomy, independent living and freedom of choice. Care policy options proposed are facilities and community networks supporting people in need of care. Moral obligations implied in the social investment scenario focus on national states to invest resources and organise proper facilities to address interests and needs of care users and care workers in order to give them freedom of choice. Moral obligations in the Active Ageing and more so in the Disability Strategy focus on the individual care users and their communities to address these needs, care workers in this scenario are supposed to be members of the community whose interests and needs are ignored.

Against this background the paper on basis of five ETHOS country reports and previous analysis of LTC conducted in the ENEPRI program has evaluated the residential care services as the form of public care par excellence and as a counterpoint of private care. Residential care services represent a form of institutionalized care supported by public resources, regulated by various healthcare and labour laws and in which care workers have formally regulated and paid jobs. However, even here not all is public; increasingly private enterprises show up in the newly developed market of care offering luxury residences for the richer populations who pay for it out of their own pockets. The questions we raised are if residential care is accessible for all who need and want it, and how residents, non-residents and care workers perceive and experience residential care. These questions relate to recognitive justice; are people recognized in their wish to live at home or in a home, do they have a free choice for one locality or another, and is it possible to keep one's dignity, preferred lifestyle and freedom to choose in a residential setting. These questions also relate to redistributive justice; do people opt for residential care as the choice in last occurrence because public support for care at home falls short, and are public services accessible for all individuals who opt for it at an affordable price? Finally, what are the boundary lines between the public and the private care domain for care workers? Here we mainly have looked at payments, working conditions and work satisfaction.

All in all, we conclude that boundary lines between the public and the private domain of care in the four countries in our ETHOS program can be imagined as a broken care chain of which the pearls are present but hard to find and even harder to rewire. Pearls can be found indeed, evaluations of residents' experiences show that residential care can be organised in such a way that elderly persons are recognized in their personal needs, dignity and choices. Moreover, some people who can afford it even choose for residential care because they prefer to live in a setting where care is continuously available. Most interestingly is the finding that boundary lines between public and private care are normatively fluid if payments are involved. At the instance of the abolition of familial financial responsibility for residential care (in Austria) the demand for residential care increased with 15 per cent. Another, though ambivalent indication might be that in all our countries, in the rich and the poor welfare states alike, waiting lists for residential care are increasing. In general, this can be explained by the ageing population of which many in their final years are in need of care, but more specifically we see that the accessibility of residential care as a public service is the consequence of a combination of various factors in which the boundary lines between public and private care are decisive. The Netherlands for instance has broken the care chain by implementing a severe de-institutionalisation reform by closing most of its lighter residential care services, the elderly homes. Consequentially, elderly and disabled persons are left with the option to be cared for at home with the assistance of home care workers and family members and/or to be on the waiting list for the nursing homes. Austria has de-familiarized financial responsibility for residential care but not

anticipated the immediate influx of elderly for residential services. In Hungary the costs of residential care are still too high for people with average incomes and the quality too poor to offer an attractive alternative for the also poor quality home care, in Portugal the private-public responsibility cannot meet up with the ageing populations, and in Turkey hardly any public residential care service is available due to the family care regime. In sum; for one reason or another, the demand for residential care is much higher than the supply of places in residential homes for disabled individuals no matter their age.

The question then is how the broken care chain can be repaired or a never-existing care chain can be installed. To answer that question, we return to the EU's Social Investment approach and the EU's Active Ageing Strategy. These approaches at first instance appear, policy-wise as antagonistic, implying that one of the two strategies must 'give in'. By recalling and unravelling the core ideological counter-values implied in the two approaches – activity-passivity, dependence-independence and institutionalisation-de-institutionalisation – it can be argued that elements can be re-thought and rephrased in such a way that boundary lines between public and private care are overcome, that moral obligations of care users are not imposed, and that care work is valued. A difference in relative emphasis on the orientations emphasized in the EU's Social Investment Strategy together with the orientations emphasized in the EU's Active Ageing Strategy, might offer a new perspective on a care policy based on some compatibility of these two approaches, this we will call the 'chain model' of care. As stated in the beginning of this report the boundary lines of public and private care are fluid, complex and hard to define. The Active Ageing Strategy however, can be read as an effort to install hard boundary lines between the two domains by encouraging older people not to pass the line from the private home to the residential care setting. The social investment approach in its turn underlines fluid boundary lines between the two domains of care by offering a stepwise transition to public residential care from state-regulated and publicly financed home care. In that approach interdependency of care users and care givers is recognized thereby overcoming the one-sidedness of the moral obligation to be and stay independent, in other words the fear of becoming dependent. Yet, the moral imperative of the Active Ageing Strategy to autonomy and participation in its turn can inspire the care chain model by the moral obligation to acknowledge and stimulate capabilities of ageing individuals and the ones that care for them in whatever setting to avoid becoming and be treated as passive dependents. Finally, the social investment approach includes the consequences of its strategy for female caregivers, albeit mainly from an economic perspective, that is their contribution to GDP and family prosperity.

Crucial of course is the question in national care policy whether residential care is viewed as the last resort because alternative options are not available or that the high demand is a matter of preference. The answer to that question relates to the moral obligations of and towards elderly and or disabled populations; what do societies owe to the more vulnerable parts of the population, are their needs recognized and if so, are resources fairly distributed to facilitate their needs and those of the care workers? Yet, what mainly matters is what alternative options for care are, what quality of care the residential settings offer in meeting the needs of the care users and if cognitive justice is done in this setting. On the first issue, the alternatives, we can say that an unbroken chain of care matters. In spite of breaking the chain by eliminating the elderly homes the Dutch chain of care exemplifies a stepwise regulated and assessment based of care from the very light forms of care (housekeeping assistance) to more severe forms of care (care and nursing at home paid for by

mandatory health insurance) and the most intensive form of care (individualized residential). Such a chain, if well-functioning, offers a tailor-made trajectory of recognition of care needs that is accessible on basis of assessment, no matter one's income, thus complies to redistributive justice claims. In all other countries in our study the chain is broken, fragmented and disturbed. Elements are missing in the recognition of care needs and the redistribution of the costs of care. Missing elements are funds for and regulations for care at home, clear assessment criteria for residential care, subsidies for the costs of residential care, individualized rooms in residential settings and tailor-made services recognizing the still present autonomy of disabled persons of all ages.

For care workers such an unbroken chain of care also meets criteria of redistributive and recognitive justice. It offers social protection for care jobs, in home care and in residential care as well as job satisfaction and therefore is crucial for their own sake and commitment to their jobs. This is a largely female job in which turn-over rates are high and unprotected work is sky rocketing. Professional care workers in residential settings are the best protected workers in the field and their complaints about work pressure indicate that redistributive justice is not realized due to misrecognition of the value of their work and their high performance. Thick boundary lines between residential care and home care still hamper recognitive and redistributive justice in both localities. Restoring the care chain by a stepwise connection of care at home and care in homes is morally and efficiently imperative in recognizing and redistributing interdependent justice.

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