

10. Just care for the elderly and disabled

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10.1 INTRODUCTION

Listening to and understanding the ‘lived experiences’ of frail elderly and adult disabled people and their care workers questions redistributive, recognitive and representative justice principles in care systems and care relationships. Disabled as well as frail elderly persons’ experiences of patronizing treatment probes recognitive justice principles because it harms self-respect, undermines self-esteem and denies them participation as full humans in social relations and society at large. Moreover, if unable to afford proper care, there is a lack of redistributive justice because they do not share in the common good as if they are not worthy of getting the resources to live the life they value. Not having a say in representative arenas might undermine political participation but also the voice to get things done. But it is not only people in need of care who might experience injustice. Those who care for them, most often women as informal or formal caregivers, also face the consequences of the undervaluation – in wage and status – of caring work. Care work is still gendered, jobs are low paid and often precarious, working conditions are suboptimal and many care workers feel that they can’t give proper care to the people who need it most.

Since the 1970s feminist scholarship on care and gender has unravelled care as a formative structural and cultural basis of gender inequality. This literature shows that the perception of care as women’s work, its assumed familialistic and domestic character, and its belonging to the sphere of reproduction diminish its worth as a valuable public good that comes with a reasonable price. Moreover, the association of care needs with ‘dependency’ contrasting, for instance, wage workers’ ‘independency’ (Fraser and Gordon 1994) does not fit with the dominant discourse of autonomous individuality and hampers the analysis of what care recipients wish and need to fully develop their capabilities. Cross-national studies (Doyle and Timonen 2007; Saraceno and Keck 2010; Genet et al. 2012) show that different care systems prevail and that some European countries have implemented improvements in care treatments and care systems for the benefit of justice. Care workers and people in need of care have contributed to those improvements by agenda setting of claims and

human rights via their representation in advocacy organizations, trade unions and political parties fighting for care workers' rights.

This chapter explores justice and care from the perspective of Nancy Fraser's claim for participatory parity, focusing in particular on justice as recognition and redistribution (Fraser 1989; Fraser and Honneth 2003) and in addition, Amartya Sen's capability approach (Sen 1985, 1999). The chapter is based on two reports of the Horizon 2020 programme 'Towards a European Theory Of Justice and fairness' (ETHOS). The reports (Anderson 2019; Knijn 2019) are ethnographic and sociological analyses of principles and discourses of justice and their realization in national care systems and practices from the perspective of both care recipients and caregivers.

The next section of the chapter outlines the idea of justice and care by highlighting the complicated relationship between (inter)dependency, participatory parity and capabilities, followed by a section on the methodology of the chapter. The third section analyses the discourses on care at the European level, their assumptions and agendas. The fourth section dives into the lived experiences of care and explores the practices and care relations between care recipients and caregivers operating under diverse care regimes, showing how care workers and care recipients cope with the main boundary lines in care, which will be identified below (passivity versus activity, dependency versus independency and residential care versus community care). The final section concludes that for justice in care to be reached, a tailor-made and stepwise care system should be developed in constant deliberation with stakeholders.

10.2 THEORETICAL FRAMEWORK

Our theoretical point of departure is embedded in the ETHOS programme that proclaims redistributive, recognitive and representative justice in order to develop individual capabilities as well as participatory parity (Chapters 1 and 4 of this volume). We understand redistributive justice as 'being secured to have access to resources in order to be capable of doing what one has reason to value'. Recognitive justice is understood as 'being acknowledged in one's identities of choice'. Representative justice is defined as 'having a say in order to participate in and give shape to the society people live, in accordance with the values they appreciate'. In outlining the three justice principles of redistribution, recognition and representation as conditions for participatory parity, Fraser mainly focuses on the political economic structures where she differentiates between production and reproduction, the latter including care (Fraser 1987, 2016).¹ Here, care is considered gender-unequally divided unpaid or underpaid 'reproductive' domestic labour that under the political economic structures of capitalism hampers women's equal participation (Fraser 1989). She suggests that these boundaries result in unequal distribution of wealth

(and poverty) amongst those participating in reproduction and undervaluation of reproductive labour of women. Ingrid Robeyns (2003) nuances Fraser's focus on participatory parity by extending the scope to the misrecognition of human diversity, that is, people who have no or limited potential to participate on the labour market because they are excluded for reasons of misrecognition on the basis of embodiment, race and/or gender. Following Robeyns (see also Anderson 2019), we find that the Capability Approach (CA) developed by Amartya Sen (1985, 1999) complements Fraser's participatory parity in CA's explicit focus on human diversity: 'At a normative-philosophical level it seems more appealing to try to develop a normative account that includes all people, and does not treat the disabled, the weak, the ill, the young, the frail, the elderly, and inmates as "special cases"' (Robeyns 2003, p. 549). Still, CA assumes that not everyone is in the same way able to convert resources into outcomes because people differ in preferences, live in various contexts and therefore have different opportunities to the beings and doings that are conditional to living a life that one has good reason to value (see Chapter 1).

While analysing justice in care systems and care relations between care workers, frail elderly and adult disabled persons and combining the overarching concept of participatory parity with CA, we are aware of the paradigmatic differences between both approaches. Where Fraser emphasizes the role of institutional structures, Sen focuses predominantly on the individual. In this contribution, we depart from the perspective of Fraser, that social problems are influenced and created by societal structures and cultural assumptions more than by individual factors, and utilize Sen's CA for pragmatic reasons. First, because care systems (insurance, facilities, cost-price systems) from the perspective of care recipients make up a specific category of the social-economic redistribution structure; the reproductive sphere that is intertwined with the mixed paid and unpaid labour market of care. Care recipients therefore depend on the redistribution of resources supporting individuals who have no or limited capacity to earn their own income. The question then is if redistributive principles in care systems meet their needs, and if and how participatory parity and the capability to live the life one values gets shape, is it by accepting the limited beings and doings or by stimulating alternative forms of integration and participation? Recognition of diversity is therefore a second condition of justice in care. Whether adult disabled people and frail elderly are awarded with enough and good quality resources depends on the acknowledgements of a wide variety of needs, identities and preferences among a population with highly diverse physical impairments. Institutionalized care systems can facilitate such a diversity, equally important are care relations that account for diverse needs, identities and preferences. Frail elderly and adult disabled people are a special case only in as far as they have care needs while they may differ in all other aspects of their lives, identities, contexts and normative

accounts of living the life one has good reason to value. Third, representative justice is at stake regarding having a voice in the kind and character of care interactions and provisions; being able to express one's needs and preferences, and getting these fulfilled, contributes to human development, despite the risk of 'adapted preferences'.

Finally, given the still gendered character of care work the issues of redistributive, recognitive and representative justice as well as capability development also bring caregivers/workers into the picture. How is their work valued in the care system? Are their preferences and identities recognized? Do care relations allow them to meet and acknowledge care recipients and what means do they have to represent their own interests and realize their own capabilities? Therefore, the main questions of the chapter are: (1) What are care-related justice principles in European discourses on frail elderly and on disabled persons? (2) To what extent could these principles be provided in care systems and care relations? (3) What are the implications for participatory parity and capabilities of care recipients and care workers?

In the literature, core concepts in analysing justice and care are 'embodiment', 'vulnerability' and 'dependency', each of which is central in demarginalizing people with disabilities and frail elderly, while gender and class inequality are core issues regarding caregivers. 'Embodiment' refers to the normativity of able-bodiedness that assumes that people with impairments due to age or physical or mental constraints per definition are *incapable* of making use of practical opportunities. Disability studies (Ingstad and Reynolds Whyte 1995; Shakespeare 2000), however, highlight the social construction of disability in a social context, work environment and physical built environment. An impairment to a body does not necessarily constitute disability. Sophie Mitra (2006) by referring to CA differentiates between *potential disability* and *actual disability*. While severe constraints indeed reduce people's potential disability they might not hamper an individual's actual disability because that

depends on whether the impairment places restrictions on the individual's functionings. At the functioning level, the focus is on what an individual values as doing (or being), and on what the individual succeeds in doing/being. In this examination, disability at the functioning level is referred to as *actual disability*. An individual is disabled if he or she cannot do or be the things he or she values doing or being. (Mitra 2006, p. 241)

In the same vein, disability and old age are associated with vulnerability, that is, 'with reduced capacity, power, or control to protect their interests relative to other agents' (Mackenzie et al. 2014, p. 6). Two amendments can be made here. First, *vulnerability* as the opposite of capability also depends on the relationship between what people aim for and what they succeed in doing or being. Second, at a more ontological level authors such as Martha Fineman

accentuate that vulnerability is not restricted to people with impairments but is ‘a universal, inevitable, enduring aspect of the human condition’ (Fineman 2008, p. 8).

This brings us to the concept of *dependency* as a social construct. Fraser has, with Linda Gordon, unravelled its contextualized meaning and its implications. ‘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’ (Fraser and Gordon 1994, p. 315). They showed that the concept of ‘dependency’ since the Industrial Revolution is no longer reserved for production workers depending on waged work but is applied to all who depend on the wage worker or the state for an income. This nowadays commonly accepted categorization defines all who are outside the capitalist production process as ‘dependents’. However, if we consider vulnerability as a universal aspect of the human condition, then the same goes for dependency. As Trudie Knijn and Monique Kremer following Joan Tronto (1993) state: ‘Every citizen is dependent on someone else in one way or another. Therefore, it is more fruitful to use an alternative perspective: All citizens are interdependent, but not always in an equal way’ (1997, p. 352). From there they conclude that in care systems and care relations it is not dependency itself that defines the relationship between care recipients and caregivers but the redistribution of resources (facilities, subsidies, insurance, budget, housing and so on), the (mutual) recognition of values, needs and identities, and the say they have in giving shape to the lives they value to live. All of which depends on structural and interactional power relations that give shape to care systems and care relations.

In conclusion, the focus of this chapter is on justice and care from the perspective of participatory parity, acknowledging that disabled and frail older people are not per definition incapable or vulnerable nor are care workers. They have their own perspective on how they value the life they want to live, and we consider them to be interdependent in their specific contexts and conditions. Lack of acknowledgement of their agency might undermine redistributive, recognitive and representative justice in care systems and care relations.

10.3 METHODOLOGY

The chapter is based upon two reports of the Horizon 2020 programme ETHOS. The first report, ‘Justice, care and personal assistance’ by Bridget Anderson (2019) is an ethnographic study of experiences of home care workers and home care recipients, the second report, ‘Boundary lines between private and public care; living independently at home or in a home’ by Trudie Knijn (2019) focuses on European social policy discourses concerning facilitating care needs in residential and home settings. Anderson’s report (2019) is

a mini ethnography and interview-based research, conducted in five European countries (Austria, Hungary, the Netherlands, Portugal and Turkey) involving care users, care workers, disabled people and personal assistants and, in some cases, their family members. A mini ethnography is a short ethnography that ‘explore[s] the feelings, beliefs, and meanings of relationships between people as they interact within their culture or as they react to others in response to a changing phenomenon’ (Fields and Kafai 2009). It facilitates understandings of norms, values and roles and is a way to capture practices and what is unsaid. The national researchers conducted field visits, accompanied care workers and personal assistants during their work, and held interviews with care workers and care recipients. The focus was on their lived experiences concerning justice claims in care. In other words, their sense of justice and fairness in care systems and care relations were contextualized in the respective national legal and policy framework and care systems (Anderson 2019). Knijn’s report (2019) expands on Anderson’s report by exploring the different national care systems and their institutional contexts through diving into the boundary lines between the private and the public domain of care. National researchers were asked to send in additional information, such as policy and legal documents and data on – changes in – national care systems, discourses and redistributive policies. In addition, the national reports have been re-analysed from the perspective of boundary drawing between public and private care systems. Central concepts of this research including recognition, redistribution, capabilities and functionings were used as sensitizing concepts, interpretative devices that allowed us to focus on issues of (in)justice concerning care relations and discourses, but at the same time allowed us to capture those instances of behaviour and meanings that did not fall within the narrow definitions of any of these concepts.

In the next two sections, the discourses and lived experiences of justice and care will be explored following the idea of boundary lines between public and private care systems and their assumptions.

10.4 EUROPEAN DISCOURSE ON JUSTICE AND CARE

Different histories and related path-dependent institutionalization characterize European countries’ justice principles in care (Saraceno and Keck 2010). All over Europe the demographic turn (Eatock 2019) worries governments and policy makers on how to balance the increasing costs of care for the growing number of needy elderly people and with doing justice to this ageing population. In that process, discourses of *Active Ageing* and *Living Independently* and *Prevention of Care* showed up. The European Union (EU) has strongly campaigned for and supported in various programmes the social participation

of disabled and frail elderly people in combination with recognizing individualized rights and responsibilities: ‘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.’² Part of the Active Ageing framework is the Independent Living strategy whose moral imperative is preventing passivity and institutionalization of elderly persons along with engaging them to become more physically and socially active. Similar assumptions underly the ‘Living Independent Movement’ that finally, after years of struggle, succeeded in getting human rights of people with disabilities acknowledged by the European Commission in its European Disability Strategy 2010–2020 that underlines the United Nations’ Convention on the Rights of Persons with Disabilities (UNCRPD).³ The European Association of Service Providers for Persons with Disabilities (EASPD), in which about 15,000 service providers are gathered, 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 EU of the UNCRPD:

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.⁴

From a justice perspective the combination seems promising for all persons with physical impairments, no matter their age; the human rights perspective might guarantee cognitive justice by acknowledging the right to actively participate on parity in society and supporting people in living the life they prefer and value to live. Redistributive justice succeeds if resources are available to condition these preferences. In that case, actual disability will disappear. Nonetheless, the strategy of Independent Living is contested (Timonen 2016; Zaidi and Howse 2017; de Sao José et al. 2019), especially its implicit and sometimes explicit creation of artificial though polarizing boundary lines of passivity versus activity, dependence versus independence and community care versus institutionalized (residential) care.

In these discourses the passivity-activity boundary line touches upon cognitive justice in the sense that the strategy of independent living, on the one hand, recognizes disabled persons and frail elderly as being capable of and having the right to active participation, thereby valuing and supporting them as dignified and valued members of society. On the other hand, activity appears in the discourse as a moral obligation condemning passive care consumers. The diversity of potential preferences and fragilities is set aside as is the option that people can decide for themselves to live the life they prefer. While it might

be that older people and adult disabled persons long for and benefit from being active or even productive, the moral imperative to be active may contrast the physical and mental preferences of frail elderly and people with disabilities who might be served better by being allowed to take a break after a long working life or a history of impairments; a just society should allow those populations with disabilities to have a voice in the way they live their lives, and must provide resources for doing so (de São José et al. 2019). The programmes are phrased in terms of ‘their own (care recipients) interests’, which suggests a patronizing approach, while it is not certain and even questionable that these programmes represent the feelings and experiences of disabled and/or frail elderly people themselves. Regarding elderly persons – from the age of 50 on – modes of subjectification position them as people who need to be addressed as a specific sort of subject endowed with specific sorts of capacities for action. This ageist discourse classifies the ageing population as passive, ignorant and isolated; persons who without intensive support do not follow up the moral imperative of being active and independent. Regarding disabled persons dealing with a wide variety of impairments the discourse ultimately ignores that passivity not only follows from disablement but also from lessened functionings that allow for passivity. All in all, these programmes ignore the diversity of older as well as disabled persons and their specific preferences.

In the dependency-independency boundary line redistributive and recognitive justice are intertwined. Being recognized as autonomous and independent persons is the core objective of the European Disability Platform and the core message of the Active Ageing framework. That discourse contributed to seeing frail elderly and disabled persons as autonomous decision makers and to getting rid of prejudicial, social, spatial and infrastructural barriers for active participation. However, by accentuating ‘independency’ as the countervalue of ‘dependency’ both programmes overlook two main side effects of the discourse. First, by assuming independency as universal modus it denies not only the fundamental vulnerability of all humans and their dependency on social relations and resources, but most of all that frail elderly and disabled persons can’t do without additional support and involved caregivers. Recognitive justice in care is an interactional and relational concept that cannot stress only the needs, interests and preferences of those that receive care. Therefore, interdependency instead of independency should be the countervalue of dependency. Second, discourses don’t develop in social-economic vacuums. The independency discourse of the disability movement is partly driven by service providers seeking a niche⁵ while the Active Ageing framework is mainly driven by budgetary reasons such as preventing rising costs of care and improving economic contributions by staying or getting employed. Pleading for independency in a context of reduced public spending on and increased marketization of care misrecognizes not only the interdependent relation-

ship between frail elderly and the caregiver, it also disregards redistributive justice by underestimating the costs of adequate public resources for staying at home as long as possible. Exemplary are the ‘best practices’ advertised in the Independent Living programme of Active Ageing. These are: guidelines and digital tools (e-health apps, smartphones, TV-based platforms and equipment) to advance social interaction and prevent loneliness of elderly people, workshops and meetings to distribute information and raise awareness, and preventing care dependency by stimulating physical activity (Knijn 2019), none of which are investments in care work.

The boundary line between residential and community care relates to the dependency-independency boundary because care dependency is in these discourses primarily understood as dependency on public resources spatially situated in public residential settings. Interestingly, community care is pictured as independent living, thereby ignoring that being dependent on the family or the community is just another form of dependency. Janet Finch (1990) already stated three decades ago that in the UK, care ‘in the community’ means care ‘by the community’ – voluntary, informal and unpaid – often coordinated and regulated by public services. The discourse on Living Independently is straightforward on this boundary line. By associating passivity, dependency and residential care as opposites of activity, independency and community care, the EU in accordance with non-governmental organizations, market parties, national and local governments have created an autonomy discourse that denies interdependency between people in need of care and caregivers, disassociates family and community care from redistributive resources and in the end disregards the concept of care as a fundamental systemic and relational concept. This development suggests what Hanne Marlene Dahl (2012) has described as neo-liberal care where services and choices have become standardized, care has been de-professionalized and discourses of the ‘active citizen’, ‘participation’ and ‘responsibility’ have become dominant ‘signifiers’ and ‘the citizen can no longer choose between passivity and activity. S/he has a moral obligation not to be passive, to care about his/her own body and mind’ (Dahl 2012, p. 285). The ultimate effect is neglecting the EU gender equality strategy because the bulk of caregiving will be on the female kin. At the same time, the European Commission (2013) presents a counter discourse in its report on long-term care (LTC) by recognizing drawbacks of relying on unpaid informal care, such as private out-of-pocket payments for informal undeclared work by mainly illegal female immigrants in precarious jobs, not guaranteeing good quality care and indirect costs in taxes foregone. Inspired by the ‘social investment approach’ (see also Morel et al. 2012), the European Commission presents good alternatives for LTC; 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.

Despite these suggestions of the European Commission in 2013 and more in line with the Independently Living discourses, all over Europe frail elderly and disabled persons are confronted with long waiting lists and shortage of available support. Long foreseen demographic developments have not encouraged Member States to invest sufficiently in LTC and by austerity politics during the 2008–15 crises residential care places were reduced, provisions for home care and personal assistance were limited and care workers were fired (see ETHOS country reports by Akkan and Serim 2019; Brito 2019; Knijn 2019; Knijn and Hiah 2019; Veres 2019; see also Eurofound 2017). Moreover, market parties could take part in the care niche expanding an already existing boundary line between the well-off and the average care receiver. These developments have consequences for justice in care relations at home and in homes in particular for participation parity and capability development, as will be illustrated in the next section by cases embedded in country contexts.

10.5 LIVED EXPERIENCES: CARE RELATIONS AT HOME AND IN HOMES

Passivity and activity in practice are not exclusionary or binary concepts. Persons can be active in decision making while passive in daily routines because they are impaired, need rest or just do not feel like participating in activities offered by volunteers, care workers or local agencies. The reverse is only thinkable if people are forced into active participation and can't decide by themselves whether they want to. Having a frail body does not mean having a frail mind. The potential disability might result in actual disability if lack of resources limits functions but equalizing passivity with actual disability denies the free will of the person in need to make an active decision for living the life one values. The latter is well illustrated by Adrienne, a care recipient who sometimes decides not to use her prosthetic leg, although it cannot always be avoided:

Even if I would pick up that leg and [throw] it in the corner ... I could. And if I would never be able to use the leg anymore, I would also make peace with it. But as long as I can, I will keep trying. [with the leg on] I sit better, and it looks better but if it hurts [with the leg on], then I will only suffer from it. And you can say, nice two legs, but if it hurts then I feel like, I have less pain without putting on the leg and this way [without wearing the leg] is fine too ... but when I visited the physiotherapist and I was not wearing the leg, he would say: next time we are going to practice walking using the bridge again, so you should wear your leg next time. (Dutch home care recipient, quoted in Knijn and Hiah 2019, p. 40)

In contrast, being disabled is not a given but made by (a lack of) resources that hamper persons in how active they like to be, if only in taking a walk, as this Portuguese woman living in a residential home explains:

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 ... for me the worst time 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 a wheelchair can't go where they want, and 'the girls' don't take them here, so we are alone most of the time. (Portuguese older woman in nursing home, quoted in Brito 2019, p. 44)

Given that care takes place in relationships, the possibility to meet care recipients' preferences bounces back on the care workers who have several though limited repertoires to cope with them. The care worker in the Portuguese nursing home not only has no time for a walk but sometimes feels that time constraints make her treat people disrespectfully: 'If there were more caregivers in each shift, we could work more slowly and could try not to hurt them ... I mean we don't do it on purpose but sometimes we can't be gentler' (Bruto 2019, p. 38). The Dutch district nurse, pressured by contracted time schemes, tends to lose patience and takes an educative, almost patronizing stand: 'You have to work efficiently because otherwise you will be out of time. It also tires me, going back and forth. And Adrienne has to be corrected in what is logical in terms of work ... With her, you have to teach her how to work systematically' (Knijn and Hiah 2019, p. 39).

Contributing to the capabilities of care recipients therefore might imply recognizing passivity as well as activity and having the resources to either let go or join in. Yet neo-liberal care practices have led to standardized procedures in the different settings and conditions of care services and needs (Dahl 2012) that might frustrate both recipients and workers. Care workers have to cope with limited time and frustrated care recipients under these conditions, which might result in moral distress (Anderson 2019; see also Tufte and Dahl 2016), especially if care recipients have not adapted their preferences to the conditions of the care systems.

Dependency versus independency are the extreme poles in a situation where people are not fully capable of living an autonomous life or to be active in society on their own capacity. The Living Independently movement in trying to avoid that situation promotes prevention of care dependency as well as the recognition of human rights of people who need support in realizing their capabilities. Cash-for-care allowances available in many European countries since the 1990s seem to offer a solution because they solve two issues at the same

time; recognitive justice by acknowledging autonomous decision making on care provisions, and redistributive justice by spending public resources on care work by relatives as in Turkey. In elderly care we see an increasing number of live-in migrant care workers (Da Roit 2010) who are vulnerable due to a lack of minimum labour protection. In such cases, care workers are dependent on the boundary lines drawn by the care users who see it as a monetary relation in which they do not account for probable homesickness or loneliness of the migrant care worker:

Leman and Sinasi 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 their 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 vacation, they were upset, and the job of the caregiver was terminated. (Quoted in Akkan and Serim 2019)

Publicly financed personal assistance is another kind of cash-for-care arrangement implemented in Austria for disabled persons to realize their capability to participate in social life. Austrian case studies show that the arrangement is supportive to service users but also that the dependency relation is turned upside down. Personal assistance users dictate the rules of the care relationship by misrecognizing the assistants and denying the interdependent care relation. The service users:

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 of the assistants. (Meier 2019, p. 17)

While the idea of cash-for-care arrangements is to secure redistributive as well as recognitive justice for people in need of care or assistance by facilitating their independency it appears to be forgotten or denied that care relations by definition are interdependent. Accentuating the independency of one party might undermine the independency of the other. The risk of misrecognition can be diminished in regulated cash-for-care systems defining the rights and obligations of both parties.

The dichotomy between *community care versus residential care* represents a political and ideological divide for redistributing care budgets among needy citizens. Communal care has been promoted mainly for budgetary reasons and is accompanied by normative ideas on activity and independency. Living

Independently, for instance, became a dominant approach in Dutch elderly care while the bulk of care is already performed by unpaid female kin. They and their care needing relatives might – if indicated – receive professional qualified home care, paid for by compulsory long-term care insurance in combination with income-based contributions provided by non-profit voluntary organizations. However, due to austerity reasons combined with a discourse on ‘Living at home as long as possible’, the government has dissolved elderly homes that formed a crucial link between home care and nursing homes. The effects are disastrous for many elderly persons who are not frail enough for a nursing home and too frail to live alone at home. The same effects are seen in Austria where residential care, condemned as it was for familiaristic reasons, suddenly became popular in that country at the time the government decided that families would be liberated from financial responsibility for elderly care. Accordingly, a paradigmatic shift occurred towards the more expensive residential care now paid for by the state. Unexpectedly, but foreseeable, this caused long waiting lists for elderly residences because the government had not anticipated this shift, hence a deficiency in residential places. That lack is present in all European countries dealing with availability and access for, on average, half of the Europeans in need of residential care – varying from about 30 per cent in the Netherlands to over 50 per cent in Austria, Hungary and Portugal (Eurofound 2017). A side effect is that only those who are prosperous enough and/or can rely on their family members are assured of their care needs being met. Well-off care users buy care on the private informal care market, following the general trend in Hungary (Széman 2015; Veres 2019) and elsewhere in Europe. In addition, residential settings for frail elderly and adult disabled persons are increasingly paid for by private resources due to a shortage of public care homes. The growing share of private residential care homes in many European countries also reveals polarization of care services between poorer and more affluent elderly. Indications are higher costs for residents of private care homes, their location in more affluent urban areas and the availability of more profitable care services (Eurofound 2017).

10.6 CONCLUSIONS

Nice and positive stories can be told about care relations between care recipients and care workers, though these stories can be told only despite and not thanks to care systems in place. All European countries are seeking for redistributive justice regarding elderly and/or disabled persons by balancing private – meaning familial – and public budgets. Most scenarios, however, fall short. When almost half of the needy elderly population in Europe is waiting for residential care, when care workers in home care and residential care don’t have enough time for persons who can’t fully help themselves, when the care

relations turn into commodified and hardly protected work relations at the cost of female workers, something is really wrong with redistributive justice in care.

This failure in just redistribution in care bounces back on recognitive justice in care; the two aspects of justice are intertwined. Participatory parity and the capabilities of care users and care workers depend on the care relationship, that is, on the efforts both parties undertake to recognize each other as partners in an interdependent relationship. When this is absent, such as in the case of the personal assistance scheme in Austria, recognitive justice for care workers fades into just a monetary and interchangeable relationship. Which does not mean that monetary care relations per se contradict recognitive justice; exemptions are possible such as in the Hungarian case of an elderly woman (age 93) who has bought care out of her own pocket because the government fails to provide adequate care and about whom the interviewer says:

She explained that she was doing her best to make the care givers' stay as acceptable as possible as she was aware of how difficult it must be for the care givers to find themselves in someone else's home for days in a row away from home. She said it was important for her to be consistent and predictable in her requests and not to act on a whim, but in a manner, which was helpful for the care givers to follow. She also said that she often did not insist on certain things, that she tried to let go of certain expectations. She gave thought about what it took for a care giver to leave her home behind and suddenly spend days and nights in a stranger's house, occupy an unknown space and at the same time perform tasks that one usually would do at home, some of these being the most mundane activities, like waking up in your bed and going to sleep in your bed, washing your cup, making a tea etc. (Veres 2019, p. 32)

Care as an interdependent relationship implies that care recipients and care workers both define the relationship, its principles and aims within the restricted conditions of the care systems that they can soften but are unable to solve. Feelings of guilt for not doing enough, moral distress and efforts to compensate by investing time and nice gestures but also training care recipients to conform to the schedules are some of the strategies of care workers to deal with restricted conditions. Adapted preferences, withholding complaints and giving compliments are strategies of care recipients who lack the recognition of their needs and identities. The opposite, authoritarian employer attitudes are strategies of care users who don't recognize needs, skills and voices of their care workers. Neither is 'Independent Living' an alternative for good quality care. What might help is to install an unbroken chain of care in which interdependent care relations recognize individual needs that must be addressed.

By recalling and unravelling the core ideological countervalues detected in the confusing EU approach – activity-passivity, dependence-independence and community care versus residential care – it can be argued that boundary

lines of public and private care are fluid, complex and hard to define in contrast to what the Active Ageing Strategy suggests. Such fluid boundary lines could be optimized by offering a stepwise transition from state-regulated and publicly financed home care services to light and successively heavier forms of public residential care depending on the articulated needs of care recipients. Acknowledging interdependency of care users and caregivers may reduce the fear of becoming dependent. Yet, the moral imperative of the Active Ageing Strategy to autonomy and participation in its turn can inspire such a care chain model by the moral obligation to acknowledging not per se the activities but the diverse capabilities of ageing and disabled individuals and the ones who care for them in whatever setting to avoid becoming and being treated as passive dependents. Finally, gender equality is crucial and should not be neglected by recognizing care users' preference for autonomy.

Crucial of course is the question in national care policies of whether residential care is viewed as the last resort because alternative options are too costly. 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? To this matter, an unbroken chain of care makes a difference. The once existing (and now broken) chain of elderly homes in the Netherlands exemplifies a stepwise regulated and assessment-based need 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 settings). Such a chain, if well-functioning, offers a tailor-made trajectory of recognition of care needs that is accessible on the basis of assessment, no matter one's income, and thus complies with redistributive justice claims. In all countries in our study this chain is broken, fragmented and disturbed or never existed. Missing elements are funds 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 the 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 care workers' own sake and commitment to their jobs. This is a largely gendered job in which turnover 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 high 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.

NOTES

1. De Sousa Santos's abyssal line would be another way to view the boundaries between production and reproduction (de Sousa Santos 2017).
2. <https://ec.europa.eu/social/main.jsp?catId=1062> (accessed 17 June 2019).
3. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/the-convention-in-brief.html> (accessed 17 June 2019).
4. In addition to representatives of disability organizations (15 non-governmental organizations), a main promotor is the European Association of Service providers for Persons with Disabilities (EASPD) in which about 15,000 service providers are gathered. <https://www.easpd.eu/en/content/our-members> (accessed 17 August 2020).
5. Ibid.

REFERENCES

- Akkan, Başak and Simla Serim (2019), 'Commodified care relations: Elderly people with disabilities and migrant care workers in Turkey', country report for ETHOS report D5.3, accessed 26 February 2020 at <https://ethos-europe.eu/>.
- Anderson, Bridget (2019), 'Justice, care and personal assistance', ETHOS report D5.3, accessed 26 February 2020 at <https://ethos-europe.eu/>.
- Brito, Laura (2019), 'Being paid to care for or to care about? National Report – Portugal', country report for ETHOS report D5.3, accessed 26 February 2020 at <https://ethos-europe.eu/>.
- Da Roit, Barbara (2010), *Strategies of Care. Changing Elderly Care in Italy and the Netherlands*, Amsterdam: Amsterdam University Press.
- Dahl, Hanne Marlene (2012), 'Neo-liberalism meets the Nordic welfare state – gaps and silences', *NORA-Nordic Journal of Feminist and Gender Research*, **20** (4), 283–8.
- Doyle, Martha and Virpi Timonen (eds) (2007), *Home Care for Ageing Populations*, Cheltenham, UK and Northampton, MA, USA: Edward Elgar Publishing.
- Eatock, David (2019), *Demographic Outlook for the European Union*, Brussels: European Parliament Research Service.
- Eurofound (2017), *Care Homes for Older Europeans: Public, For-Profit and Non-Profit Providers*, Luxembourg: Publications Office of the European Union.
- Fields, Deborah A. and Yasmin Kafai (2009), 'A connective ethnography of peer knowledge sharing and diffusion in a tween virtual world', *International Journal of Computer Supported Collaborative Learning*, **4** (1), 47–68.
- Finch, Janet (1990), 'The politics of community care in Britain', in Clare Ungerson (ed.), *Gender and Caring: Work and Welfare in Britain and Scandinavia*, Hemel Hempstead: Harvester Wheatsheaf, pp. 34–58.
- Fineman, Martha A. (2008), 'The vulnerable subject: Anchoring equality in the human condition', *Yale Journal of Law and Feminism*, **20** (1), 1–23.
- Fraser, Nancy (1987), 'Women, welfare and the politics of need interpretation', *Hypatia*, **2** (1), 103–21.

- Fraser, Nancy (1989), 'From redistribution to recognition? Dilemmas of justice in a "Post-Socialist" age', in Cynthia Willett (ed.), *Theorizing Multiculturalism: A Guide to the Current Debate*, Malden, MA: John Wiley & Sons, pp. 19–49.
- Fraser, Nancy (2016), 'Contradictions of capital and care', *New Left Review*, **100**, 99–117.
- Fraser, Nancy and Linda Gordon (1994), 'A genealogy of dependency: Tracing a keyword of the U.S. welfare state', *Signs*, **19** (2), 309–36.
- Fraser, Nancy and Alex Honneth (2003), *Redistribution or Recognition? A Political-Philosophical Exchange*, London and New York: Verso.
- Genet, Nadine, Wienke Boerma, Madelon Kroneman, Allen Hutchinson and Richard B. Satman (eds) (2012), *Home Care across Europe*, Copenhagen: World Health Organization.
- Ingstad, Benedicte and Susan Reynolds Whyte (eds) (1995), *Disability and Culture*, Berkeley, CA and London: University of California Press.
- Knijn, Trudie (2019), 'Boundary lines between private and public care; living independently at home or in a home', ETHOS report D5.4, accessed 26 February 2020 at <https://ethos-europe.eu/>.
- Knijn, Trudie and Jing Hiah (2019), 'Competing claims of justice in the private household: The Dutch case', country report for ETHOS report D5.3, accessed 26 February 2020 at <https://ethos-europe.eu/>.
- Knijn, Trudi and Monique Kremer (1997), 'Gender and the caring dimension of welfare states: Toward inclusive citizenship', *Social Politics. International Studies in Gender, State & Society*, **4** (3), Special Issue, 328–61.
- Mackenzie, Catriona, Wendy Rogers and Susan Dodds (eds) (2014), *Vulnerability: New Essays in Ethics and Feminist Philosophy*, Oxford: Oxford University Press.
- Meier, Isabella (2019), 'You really need to hold back, you are only the surrogate eye. Personal assistance in Austria', country report for ETHOS report D5.3, accessed 26 February 2020 at <https://ethos-europe.eu/>.
- Mitra, Sophie (2006), 'The capability approach and disability', *Journal of Disability Policy Studies*, **16** (4), 237–47.
- Morel, Nathalie, Bruno Palier and Joakim Palme (2012), *Towards a Social Investment State? Ideas, Policies and Challenges*, Bristol: Policy Press.
- Robeyns, Ingrid (2003), 'Is Nancy Fraser's critique of theories of distributive justice justified?', *Constellations*, **10** (4), 538–54.
- São José, José Manuel Sousa de, Virpi Timonen, Carla Amado and Sérgio Santos (2019), 'From "active" to "capable": A capability framework for policy and practice on ageing in later life', in Mara Yerkes, Jana Javornik and Anna Kurowska (eds), *Social Policy and the Capability Approach*, Bristol: Policy Press, pp. 41–60.
- Saraceno, Chiara and Wolfgang Keck (2010), 'Can we identify intergenerational policy regimes in Europe?', *European Societies*, **12** (5), 675–96.
- Sen, Amartya (1985), 'Well-being, agency and freedom: The Dewey Lectures 1984', *Journal of Philosophy*, **82** (4), 169–221.
- Sen, Amartya (1999), *Development as Freedom*, New York: Knopf.
- Shakespeare, Tom (2000), *The Disability Reader: Social Science Perspectives*, London: Continuum.
- Sousa Santos, Boaventura de (2017), 'The resilience of abyssal exclusions in our societies: Toward a post-abysal law', *Tilburg Law Review*, **22** (1–2), 237–58.
- Széman, Zsuzsa (2015), 'Transition of long-term care in Hungary', *European Journal of Mental Health*, **10** (2), 245–55.

- Timonen, Virpi (2016), *Beyond Successful and Active Ageing: A Theory of Model Ageing*, Bristol: Policy Press.
- Tronto, Joan (1993), *Moral Boundaries: A Political Argument for an Ethic of Care*, New York: Routledge.
- Tufte, Pernille and Hanne Marlene Dahl (2016), 'Navigating the field of temporally framed care in the Danish home care sector', *Sociology of Health & Illness*, **38** (1), 109–22.
- Veres, Judith (2019), 'Left in the cold. Informal home care in Hungary', ETHOS country report for ETHOS report D5.3, accessed 26 February 2020 at <https://ethos-europe.eu/>.
- Zaidi, Asghar and Kenneth Howse (2017), 'The policy discourse of active ageing: Some reflections', *Population Ageing*, **10** (1), 1–10.